The University of Alberta

Elderly People Attending Day Programs: The Perceptions of Participants and Caregivers

by

Louise M. Folkmann ©

A Thesis

Submitted to the Faculty of Graduate Studies and Research in partial fulfillment of the requirements for the degree of Master of Nursing.

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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled Elderly People Attending Day Programs: The Perceptions of Participants and Caregivers submitted by Louise M. Folkmann in partial fulfillment of the requirements for the degree of Master of Nursing.

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ABSTRACT

Care of the elderly has become a major concern of Canadian society as the growing elderly population and increasing demand for services challenge existing resources. There is growing recognition that community-based alternatives to institutional services must be made available and accessible to elderly people. Health services such as day programs that promote overall well-being, independence, and quality of life have emerged as viable options in supporting the community living arrangements of frail elderly people. Researchers examining day programs and their clients and caregivers have focused primarily on objective outcome measures. Little emphasis has been placed on the experiences and perceptions of program clients or their caregivers. The purpose of this research was to focus on the perceptions of the person attending a day program and on primary caregivers. Secondary analysis of interview data provided in an earlier study by 18 clients and 17 caregivers was completed using a thematic form of content analysis. The analysis revealed that day programs enable clients to maintain independence and enhance their quality of life. They also provide caregivers with opportunities for socialization and support and provide freedom from the demands of caregiving. Both clients and caregivers report being highly satisfied with the beneficial effects they perceive as a consequence of attending the program. The researcher concludes that day programs play a vital role in supporting community living arrangements of frail elderly people.

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Chapter I:

Introduction

The proportion of elderly people in our society is growing rapidly and is expected to continue to expand at an accelerated rate. In 1991, 11.6 percent of the Canadian population was aged 65 or older, a tenfold increase over the past 80 years (Statistics Canada, 1992). By the year 2021, 14-17 percent of the Canadian population is expected to be 65 or older, an increase of over one million people (Rapelje, 1992). The most dramatic increase is in the segment of the population commonly referred to as the old-old (over 85), which is increasing at six times the rate of the general population (Dunphy Brown, 1988).

Although advances in medical technology and knowledge have contributed to population longevity and the treatment of many life-threatening illnesses, less success has been demonstrated in controlling the chronic illnesses and disabilities of old age. It has been estimated that for each good functional year that is added to life, 3.5 compromised years are also added (Lorenson, 1992). Consequently, greater demands are placed on health care services, and few people will reach the end of life without some period of dependency (Brody, 1985; Wolinsky, Coe, & Mosely, 1987). The oldest old experience a higher degree of physical impairment than any other age group and, not unexpectedly, utilize a disproportionate amount of all health care resources (McMahon, 1988). Care of the elderly has become a major concern of Canadian society as increasing numbers, longevity, and dependency constitutes a significant challenge, the scope of which is unprecedented in human history.

To effectively meet this challenge, there is growing recognition that long term care for frail elderly people must move beyond the traditional cure-oriented medical model (Green, 1991; Hogan, 1990; Lorenson, 1992; Rapelje, 1992). Health care professionals and individuals generally agree that institutionalization is not always the most desirable or cost-effective alternative. Community living should be a viable option for people, however, because community based health services are insufficient and uncoordinated, community living may mean living in isolation and fear of excessively burdening family members (Muiznieks, 1988). There is growing recognition that what is required is a continuum of health services (from institutional settings to community services) that promote overall well-being, independence, and quality of life. Adult day programs are a vital link in the continuum of long term health care, potentially supporting the independence and needs of the community based elderly and the family caregiver.

Chapter II:

Rationale

Literature Review

Dependency of the Elderly

The challenges confronting the elderly person and his or her family in the face of failing health and disability are considerable. Although the vast majority of elderly people enjoy good health and live independently without instrumental assistance from others, 10-18 percent suffer from some form of chronic illness or disability which restricts their independence in conducting activities of daily living, and 5-8 percent live permanently in institutional settings where formalized caregiving services may be provided (Lorenson, 1992; Melanson & Meagher, 1986).

The movement of elderly people from their homes into a long term care facility is generally considered a "last resort." People prefer to remain in their own homes and strive to be independent for as long as possible (Rutman & Freedman, 1988; Kasl & Rosenfield, 1980). Families provide substantial support in caring for ill or elderly relatives, and play a significant role in delaying or preventing the need for institutionalization (Keating, Kerr, Warren, Grace, & Wertenberger, 1992; Shanas, 1979; Dunphy Brown, 1988; Brody, Poulshock, & Masiocchi, 1978; Hogan, 1990). Only when individual and family resources have been exhausted is long term placement considered. Adult day programs can be considered an essential alternative in adequately supporting elderly people with failing health in their desire to maintain community living.

Adult Day Programs

Adult day programs, introduced in Russia in the early 1930's (Cummings, Kerner, Arones & Steinbock, 1985) are one of the rapidly growing options that have become available as the conception of long term care has expanded to encompass a wide range of community based services. First established in Alberta in 1973, day programs are currently accessible selectively in the province. Although day care for adults has been promoted as a cost effective means of providing community based health care services to frail elderly people, the establishment and evaluation of these programs has proceeded relatively slowly.

Although other models of adult day programs have been identified, two basic types of programs for the frail elderly are most common: day hospital and day support programs. Day hospitals focus more closely on intensive rehabilitation and restoration, while day support programs provide socialization, recreation and respite. Each program offers a unique blend of services to clients based on the particular needs and resources of the community it serves. Participants are able to return each night to their own homes and do not have to permanently leave their spouses, families, neighbors and friends. They remain in contact with their familiar community and social environment thus maintaining a sense of continuity (Wood & Harris, 1976). Commonly stated objectives of various programs are as follows: to prevent or delay institutionalization; to provide meaningful recreational activities; to assist clients to maintain and/or improve their physical and mental health status; to provide increased opportunities for social interactions; to provide emotional support and respite for caregivers; to provide a cost-effective alternative to institutional or home services; to provide basic services such as bathing or meals; and to provide regular health assessment and monitoring (Astill-McNish & Stevenson, 1984; Gerard, 1988; Jackson, 1983; Ross Kerr, Warren, & Godkin, 1995; Savage & Madsen, 1990). All adult day programs, however, share a common theme: they provide a non-institutional support system for individuals who would otherwise have difficulty in maintaining their independence in a community setting.

Evaluation of Adult Day Programs

As the role of adult day care as a community based health service for impaired adults has become more prominent, researchers have turned their attention to assessing its impact. The programs reviewed in the literature vary enormously by program model, services offered, staffing, clientele, and funding source. There are also significant methodological differences among the studies cited, ranging from anecdotal accounts to experimental designs. The common theme, however, is that the evaluators are attempting to discover the consequences of providing day care to impaired adults.

An early British experimental study examined the extent to which day treatment would improve the health of elderly people living alone (Woodford-Williams, McKeon, Trotter, Watson & Bushby, 1962). The researchers found that during the first 6 months of attendance in the day program, clients spent more days in hospital, probably because of regular medical examination and the detection of abnormalities. However, in the second 6 months of the study, the day program group demonstrated significantly reduced rates of hospitalization, psychological depression, and improvement in morale and independence.

Greene, Lovely, and Ondrich (1993) utilized data collected from the United States National Long Term Care Chanelling demonstration project (n=3,446) to determine the cost-effectiveness of community long term care services as a substitute for nursing home care. Their analysis revealed that additional services such as day programs can be beneficial for many individuals, potentially reducing the risk of institutionalization and expected long term care costs.

Research conducted by Pablo and Cleary (1982) lends support to the proposition that day programs delay or prevent institutionalization. In this Ontario study of 167 day hospital clients, one-quarter were discharged from the program to their homes, leading the researchers to conclude that "a reasonable success in supporting the elderly to live in the community, who might otherwise be in active treatment hospitals, nursing homes, or continuing care facilities was noted" (Pablo & Cleary, 1982, p. 181).

Lawton, Brody, and Saperstein (1989) also found that respite services, including day programs, delayed institutionalization. They conducted a randomized, experimental design study where the treatment group was provided with a variety of respite services over a one year period. Families who utilized respite services were able to maintain their impaired relative in the community significantly longer.

Although many writers view adult day care as an alternative to institutionalization, more recent literature indicates that adult day care is serving a slightly different segment of the frail elderly population. Findings of a recent national survey of day care participants in the United States indicate that "while the majority of day care participants are functionally dependent elderly, white, unmarried females, almost a third of whom suffer from a mental disorder, they do not closely resemble nursing home residents. They are younger, more likely to be married and less frequently mentally impaired" (Weissert, Elston, Bolda, Cready, Zelman, Sloane, Kalsbeck, Mutran, Rice & Koch, 1989, p. 648). Adult day care seems to be meeting the caregiving needs of many elderly who are being supported by spouses, adult children and others. Thus, adult day care and other community based services do not appear to be replacing formal care but rather complementing it.

In a study to evaluate day hospital care in rehabilitation medicine as an alternative to intensive inpatient care, it was found that those who attended the day program demonstrated no essential difference in physical or functional outcomes (Cummings, et al., 1985). Based on the objective results of each form of treatment, the researchers conclude that the quality of care provided by the day hospital is at least equal to conventional hospital treatment. They also determined that day hospital care (running at full capacity and with research costs removed) is more cost effective.

Strang and Neufeld (1990) employed a descriptive design to evaluate an Alberta day program. They found that the program was successful in meeting its stated objectives: frail elderly client's level of functioning was maintained and caregivers found relief (minimal) from burden, sustaining them in their role. In another Canadian study, researchers utilized a randomized controlled trial to determine whether there was a difference in the quality of life between elderly clients receiving day hospital care and those receiving conventional care (Eagle, Guyatt, Patterson, Turpie, Sackett & Singer, 1991). They found that there was no significant difference in the ability to perform activities of daily living or in quality of life between the two groups, although the control group did demonstrate outcomes that were slightly more favorable. They concluded from these findings that there was "little support for the hypothesis that care provided at geriatric day hospitals improves function or quality of life in the elderly" (Eagle, et al., 1991, p. 704). Another finding of considerable interest is that functional status deteriorated over time in both groups, lending credence to the belief of some authors that outcome expectations may be unreasonable.

In a study of clients in one British Columbia day center, clients and their families were interviewed a number of times: upon admission to the program, during attendance, and following the center's closure (Jackson, 1983). During their attendance, clients demonstrated improved social skills, communication, and self esteem, as well as minimal improvements in their functional abilities. In their view, exercises were useful, but social activities were the most important to them. Families reported improvements in their relationship with the client and were grateful for the rest, privacy, and time that the day center allowed them. Once the center closed, none of the clients were able to maintain their improved health status. They reported an increase in confusion, anxiety, depression, dissatisfaction, and institutionalization. Families found that they were more fatigued and that they had less opportunity for social activities. Although these findings are impressive, a major limitation is that the number of clients interviewed was very small (n=8), and that half of them were interviewed with family members present, possibly affecting their responses.

In a recent, comprehensive project, researchers conducted an evaluation of the Adult Day Program Demonstration Project in Alberta (Ross Kerr, et al., 1995). Initiated by Alberta Health, the demonstration project was instituted as a measure to maintain the frail elderly in community living arrangements and to delay and/or prevent institutionalization whenever possible. A number of measures were administered to clients and their caregivers to determine the effects of day program attendance on functional status, and physical, mental, and social health. Although there were no significant differences on any of the measures, the quality of life for cognitively intact clients increased slightly and clients reported that they were very satisfied with the programs. Caregivers were able to maintain their health and quality of life while continuing their caregiving role. Again, although not significant, burden did decrease slightly over time. The researchers conclude that "modest or negligible change in client outcomes in terms of health and social functioning over a period of day program attendance should be considered to be a successful intervention in terms of its importance in supporting the client in maintaining health and social status necessary for continued community living" (Ross Kerr, et al., 1995, p. 215). They also recommend that day programs be considered an integral part of the long term care system, accessible to all who would benefit from them.

The findings of those who have studied the impact of adult day programs on clients and their caregivers have been relatively consistent. Although many studies provide support for the continued use and development of day programs, others present conflicting or questionable evidence. Several explanations for these contradictory findings have been suggested. For instance, many studies focus primarily on measuring changes in physical health and/or functional ability, with the expectation that conditions will improve. Because the group of individuals utilizing day programs tends to be very fragile, there often is minimal or no improvement in their condition. The focus on improvements in physical and functional status when evaluating impact is perhaps unrealistic given the frailty of these clients (Gaitz & Varner, 1980). A more realistic expectation may be the maintenance of function. If the person is able to carry on activities that are essential to their well-being, the process of deterioration may be delayed and a degree of health promotion achieved. Anecdotal evidence reveals that clients and their caregivers are highly satisfied with day programs and the perceived benefits of attending.

Another major problem results from the enthusiasm of the health care team in the process of assessment. With vigorous, routine assessments previously undetected medical problems requiring diagnostic testing and hospital care may be discovered. This sabotages the program evaluation as day program clients may utilize the health care system more extensively than control clients who do not have the benefit of ongoing assessment (Brocklehurst & Tucker, 1982). Whether this early detection and treatment of problems enhances the health and well-being of the frail elderly is not known.

Program evaluations often lack generalizability of findings for several reasons. Program characteristics and variations in the design and conduct of research studies make it difficult to draw conclusions from the evaluation of particular programs. Each program is unique in terms of who uses it, what staffing and services are offered, its objectives, and its costs and revenues, making comparisons across programs problematic. Researchers employ a diversity of designs in order to capture information about varying outcomes such as cost-effectiveness, improvements in physical health or functional ability, the delay or prevention of institutionalization, psychological health, and the individual's perceptions and satisfaction with programs. Finally, research conducted outside of this country may not be relevant to programs established within the Canadian system of health care delivery.

Caregiver Issues

Although an important focus of evaluation studies is on the clients who attend day programs, many include caregiver assessments of programs as caregivers are essential in providing the support necessary in order for frail clients to continue to maintain community living arrangements. Evidence is mounting to suggest that the informal caregiving network may be more important in predicting institutionalization than client characteristics (Kirwin & Kaye, 1991). Despite the recognition that informal caregivers provide substantial support to community living elderly, financial incentives have historically centered on acute care and institutional settings rather than on community based services. Currently, very few public policies exist that assist informal caregivers with their tremendous task of providing quality care to their loved ones.

In the past, Canadian families provided most of the necessary care for their ill or dependent relatives. There is considerable debate in the literature as to whether the family caregiving function is diminishing in importance. Researchers point out that the occurrence of industrialization and urbanization has wrought major changes in all aspects of family life including elderly parent-adult child relationships. Specifically, society is geographically mobile, women are increasingly involved in workplace activities, and the nuclear family arrangement is common, separating the elderly from their children. Individuals rely more heavily on social support programs and formalized caregiving systems as a result of technological sophistication and increased government involvement in what was once the exclusive domain of the family (Keating, et al., 1992; Shanas, 1979).

Despite these continuing social and technological influences, strong familial ties persist. Most families do not abandon their elderly, but in fact provide substantial support. It is estimated that 80 to 90 percent of home health care is conducted by the family (Brody, 1985; Hays, 1988). Not only do families conduct the majority of care, they play a significant role in delaying or preventing the need for institutionalization. Brody, Poulshock, and Masiocchi (1978) compared two groups of elderly persons: residents of nursing homes (n=140) with residents living at home who were receiving home care support (n=46). They found similar levels of functioning in both groups, ranging from those who required little or no assistance with activities of daily living, to those who required complete and total assistance. The critical variable which explained why individuals with similar levels of ability were residing in different residential facilities was the care of supportive family members. Shanas (1979) analyzed data from a national U.S. survey of the noninstitutionalized population aged 65 and older. She found that the presence and support of immediate family made it possible for the elderly to live at home and that families expend a great deal of effort to provide quality care and avoid institutionalization of their elderly relatives. Shapiro and Tate (1985) reached similar conclusions. They examined a large sample of community living elderly (n=3,383) and found that many elderly who were equally or more disabled than those in long term care settings continued to remain at home in the community because of the care and support of their families.

Although the important role that families play in caregiving is not disputed, there is growing consensus that it is not the "family" that provides the care, but a solitary person, usually female (Keating, et al., 1992; Hogan, 1990; Green, 1991). "Elder care joins housework, child care, food preparation, and shopping as an arena of unrecognized, unpaid work that is expected of women because they have always done it" (Green, 1991, p. 6). Most commonly, the caregiver is either the spouse or daughter of the elderly person, but care is also provided on occasion by friends and neighbors (Stroller & Earl, 1983; Smallegan, 1985; Young & Kahana, 1989). Women's motivation to care may be considered a natural extension of the nurturant role and a part of the expectations associated with being a woman.

The willingness of families to provide care cannot be equated with ability or competence. The responsibilities of providing care for an older adult can place the caregiver at risk for negative physical, emotional, and social outcomes and may compromise the ability of the informal helping network to cope with frail elders on a long term continuing basis. The time and energy demands of parent care can be overwhelming and can collide dramatically with individual needs, career and family activities. The threat of burnout from role overload is significant as competing demands exceed the caregiver's personal resources to meet them. Finances become an issue for caregivers who sacrifice income and future health and retirement benefits to care for parents and who assume most of the financial burden for maintaining the elderly person's health and supporting daily living. Powerful emotional reactions such as guilt, resentment, anger, sadness, and embarrassment can result from the increased intimacy required in caring for aging parents. Previously established dynamics that maintained parents in positions of power and leadership may be threatened as it becomes a struggle to create dynamics that circumvent the feeling of role reversal. Caregivers themselves are likely to be elderly, and may suffer from feelings of chronic fatigue and damage to their physical health. Under conditions of chronic and progressive impairment, caregiving may expand to the point where it occupies virtually the entire relationship. It is a complex and unpredictable role, changing as the person's health status, living arrangements, available assistance, and monetary resources change (Green, 1991; Novak & Guest, 1989; Pearlin, Mullan, Semple, & Skaff, 1990).

Given the overwhelming demands that caregiving can place on the caregiver, one may ask why it is that people continue to care for others. In a study of 40 women caregivers of frail elderly or mentally ill relatives, Guberman, Maheu and Maillé (1992) examined the reasons they became caregivers. They found that there are a multitude of psychological, political and social factors that come into play in caregivers' decisions to assume responsibility for a dependent family member. However, a significant factor in the decision to become a caregiver in many cases was the unavailability of other family members and the inadequacy of community and institutional alternatives. Thus, in order to support informal caregivers in their role, social policy must change to a family oriented system which recognizes and complements the vital services provided by informal helpers. One of the major objectives of day programs is to address this need by providing respite services which serve to sustain informal caregivers in their caring roles.

George and Gwyther (1986) conducted a correlational study comparing the informal caregivers (n=510) of cognitively impaired older adults to established population norms of non-caregivers. Fully 59 percent of their sample expressed the need for more help than they received with their caregiving responsibilities. They also found that the characteristics of the caregiving situation and the available resources most directly affected caregiver well-being. They conclude that although demonstrable burden remains, respite from day to day caregiving responsibilities has beneficial impact.

In a large study (n=753) of noninstitutionalized elderly, investigators examined the psychiatric, medical, nutritional, economic, and social problems of the older person (Stroller & Earl, 1983). They found that the majority of community living elderly were self-sufficient and that the family was a major source of support for those who require regular help. However, four percent of their sample reported needing more help than they got in a particular task area, representing a significant number of people.

In a four year longitudinal study of the caregiving experiences of family caregivers of persons with dementia (n=338), the majority of the sample did not perceive that additional community based services such as adult day care would have delayed institutional placement. However, fully 40% reported that the availability of at least one additional service would have delayed the nursing home placement of their relative (Collins, King & Kokinakis, 1994).

Zarit, Todd, and Zarit (1986) reported similar findings in their longitudinal study of caregiver burden. Families reported that the level of assistance that they received (both formal and informal) was relatively low. They expressed a need for respite services which they had been unable to obtain or could not afford. They conclude that carefully planned interventions that focus on improving coping with everyday problems and that providing opportunities for respite may effectively relieve some of the burden caregivers experience. In a number of evaluation studies, caregiver burden was not impacted through client attendance at day programs even though caregivers were very highly satisfied with the programs (Ross Kerr, Warren & Godkin, 1995; Lawton, Brody & Saperstein, 1989; Weissert, et al., 1989).

Graham (1989) measured the level of caregiver strain in those caring for family members with dementia before and one month after the client's placement in a day program. Of the fifteen caregivers studied, postplacement burden scores did not support anecdotal reports of decreased strain. The researcher offers several explanations for the failure of the sample to benefit significantly from the respite offered by adult day care. Several caregivers viewed their decision as evidence of failure to manage and successfully care for their family member, preventing them from utilizing adult day care to its fullest potential. Another possible explanation is that a crisis precipitated the use of respite care, resulting in increased caregiver stress and adjustment difficulties. Finally, the time frame of the study may not have been adequate to allow the caregiver to regain equilibrium and to moderate burden. Surprisingly, burden has been found to persist even after the elderly person is institutionalized and is receiving formal care (Rosenthal, Sulman, & Marshall, 1992). Perhaps methods which focus on the perspective of the person rather than objective burden measures would be more useful in attempting to understand the impact of day programs.

There is an absence of reported reliance on formal service providers by clients and their caregivers. In a study describing the factors affecting family involvement in nursing home care, York and Calsyn (1977) found that families did not utilize alternatives to institutional care even though many of the alternative services were known to them. Johnson & Werner's (1982) findings were similar. In a study exploring the decision making process and experiences prior to nursing home placement, they found that few families had tried any alternatives to institutionalization. Barber, Paton and Wishnia (1993) surveyed a stratified random sample of 1,913 households to determine awareness of and the perceived need for adult day care. They estimate that 1.25% of all households would have an adult member who would need and use adult day care but that utilization experience is much lower than perceived need. And in an investigation of the process of nursing home admission, Smallegan (1985) found that very little care had been provided with community health resources. Only two clients out of the entire sample (n=288) had attended a day care program prior to their admission!

In a large study examining the utilization of community services, researchers asked caregivers (n=597) of noninstitutionalized dementia sufferers to identify services they knew were available in their area and also which services they utilized and how frequently they had utilized them. Forty-three percent of respondents were aware of one or more formal community services available. Among those who knew of available services, 57.5% utilized at least one of them. Evident in these findings is that awareness of available services is moderate at best. When known to be available, need and the person's level of impairment were considerations in determining whether or not the services were utilized. Many of the caregivers who were not yet ready to access community services reported that the person was not at a stage of illness that required formalized care indicating that the informal network was still capable of managing (Caserta, Lund, Wright & Redburn, 1987).

This lack of utilization of community resources has led health care planners to question their utility to clients they purport to serve. There are a number of other explanations for underutilization. There may be a shortage of available services or personnel, the eligibility requirements may be too restrictive, the needs of the elderly person may exceed the program's short term, day time coverage, the older person may be reluctant to contact formal agencies, there may be a lack of awareness of the assistance that is available, people may prefer another source of assistance, the program may be too costly or inaccessible because of logistical difficulties such as transportation and program location, or there may be a general reluctance to rely on others for help until a crisis point is reached in the caregiving process.

Statement of the Problem

Care of the elderly has become a major concern of Canadian society as the growing elderly population and the demand for services challenges existing resources. Health services that promote overall well-being, independence, and quality of life are required to support community living arrangements as a viable option for frail elderly people. Day programs were established to support the independence and needs of the community based elderly and the family caregiver. The majority of literature evaluating day programs has focused on objective measures of physical health and functional ability, while caregiver assessments have centered on the measurement of burden. Although elderly people and their caregivers have reported being highly satisfied with day programs, their satisfaction has not always translated into favorable outcomes in terms of burden, physical, mental, emotional, or social health. Thus, contextual data of a descriptive, qualitative nature which focuses on the experience of the day program participant and his or her informal caregiver may be valuable in supplementing existing knowledge.

Purpose of the Research

The purpose of the research was to describe the perceptions of clients regarding the day programs they attended and the impact those programs may have had on the process of managing their health. In addition, the perceptions of participant's primary caregivers and the impact day program attendance may have on the caregiving role was explored. The research questions were as follows: "What are the perceptions of clients regarding the day programs they attended and the impact those programs may have had on the process of managing their health?" and "What are the perceptions of primary caregivers regarding the client's day program attendance and what impact did program attendance have on the caregiving role?". Terms are defined as:

Day programs: settings which provide community-based health care services to frail elderly people

Primary caregiving: the activities and experiences of a single individual in providing help and assistance to relatives or friends who are unable to provide for themselves

Limitations of this Study

A major limitation of this study is that data analysis occurred following data collection. Ideally, the phases of data collection and analysis take place simultaneously so that emerging themes and relationships serve to guide further data collection. Another limitation is that the researcher was not able to confirm her findings with the participants. This limitation was addressed to some extent through review of the findings by one of the original researchers who is an expert in this field.

Chapter III:

Research Design

Method

The researcher's purpose was to describe the perceptions of clients and caregivers regarding day programs as well as the impact day programs have on them. Because day programs in essence are targeting two diverse groups - clients and caregivers - gaining the perspective of each group was thought to be extremely advantageous in terms of understanding the experience. In particular, how people conceptualize attending a day program, the meaning attending a day program has for clients and caregivers, and how they cope or manage differently with this service was of interest. The researcher began with the assumption that the best source of information about this is people themselves. Thus, a qualitative, exploratory method was utilized to address the research questions as qualitative methods are most suitable to explore, understand, and describe a phenomenon from the perspective of the person experiencing it (Field & Morse, 1985). Based on a review of the literature, it was evident that little emphasis had been placed on understanding the impact day programs have on participants and caregivers from their viewpoint. Consequently, an exploratory method was selected as it allows the researcher to obtain a multidimensional view without the constraints of confining measurements or experimental controls being placed on the phenomenon being studied (Field & Morse, 1985).

The study involved secondary analysis of interview data. Secondary analysis makes use of data gathered for the purposes of a primary research analysis but looks at questions not addressed by the original investigator, or addresses the same questions using different methods of analysis (McArt & McDougal, 1985). Secondary analysis is advantageous for a number of reasons: it enables beginning researchers to utilize the data collecting skills of more experienced and sophisticated researchers, it allows access to large data sets that would not be easily or economically collected independently, it facilitates the research process, it provides the opportunity for interaction with colleagues on topics of mutual interest, it generates knowledge as data is re-examined, it is economical in monetary terms as well as in time and effort, it does not impose on clients or overuse similar client populations, and it allows the researcher to maintain psychological distance and objectivity (Herron, 1989; Moldanado, 1981). However, there are a number of risks inherent in the use of secondary analysis. An awareness of the risks is essential so that their effects may be minimized. The research is entirely dependent on the reliability of the original data collection and entry, methodological errors in the original study may be difficult to detect, the opportunity to appreciate the process of data collection is eliminated, and there may be information missing that seems crucial to the secondary researcher but which has not been obtained in the original data collection (Burnstein, 1978; Gooding, 1988).

The data was provided by a group of clients attending day programs and their caregivers. The clients and caregivers were interviewed as part of an earlier and larger study evaluating the Adult Day Program Demonstration Project in Alberta (Ross Kerr, et al., 1995). The original study was conducted to evaluate, draw conclusions, and make recommendations regarding the role of day programs in the long term care system in Alberta. Fourteen day programs were included in the study; eight were part of the demonstration project and six served as comparison sites. Managers of each site provided a descriptive profile of their program and agency managers who referred clients (n=16) completed a questionnaire, allowing a description of programs, costs, and utilization. Clients (n=571) were described utilizing data extracted from their records. Information about program outcomes such as the client's health status, functional status, life satisfaction, and satisfaction with the program as well as caregiver's life satisfaction, subjective burden, opinion on institutionalization, and satisfaction with the program was obtained through the use of various instruments (see Appendix A). The instruments were administered directly to clients (n=147) and caregivers (n=122) using interview methods across five time intervals: two months before admission into the program, immediately prior to admission, immediately after admission, two months after admission, and six months after admission to the day program. A purposive sample of clients (n=18) and caregivers (n=17) participated in a qualitative component of this study. Unstructured interviewing techniques were employed with this sample at the time of the final interview in the time series. Data obtained through unstructured interviews was subjected to a very preliminary analysis in order to elicit further information relating to the caregiver and client experiences in the day programs. In this beginning analysis, no in-depth attention was paid to the themes or patterns that arose. Instead, the use of this data was primarily illustrative in nature, adding examples and experiences of participants to the analysis of the objective measures that were administered. The focus of the present study has been to give primary attention to this interview data. In this study, a thematic form of content analysis was used to examine the transcripts of the open-ended interactive interviews.

Sampling

In the original study, eighteen clients of day programs and seventeen caregivers were interviewed for approximately one hour at the end of the data collection phase. Most of the sample was composed of dyads or pairings of clients and their primary caregiver. However, in some cases the client did not have a caregiver or their caregiver did not wish to participate so other caregivers were selected. All participants were selected purposively to represent different programs, genders, ages, and varied relationships to one another. Purposive sampling allows for the deliberate selection of individuals who have specific characteristics, experiences, or knowledge of the research topic (Morse, 1991). It is acknowledged that the viewpoints of other program stakeholders such as program directors, referral personnel, program staff, and volunteers are not included and are beyond the scope of this study. Although the individuals in the study were not known to the researcher, demographic information regarding the sample in general was available. Additionally, a profile describing each participant was developed as the transcripts were reviewed in order to provide contextual information.

Data Collection

Unstructured interviewing techniques were utilized to elicit data relating to the caregiver and client experiences in the program. The guiding questions were: "Tell me about your experience in the day program" and "What effect has the day program had on your life and on the lives of your family and friends?" (see Appendix B). These unstructured, general directives allow the person to respond to and explore the topic from a unique perspective without constraint or influence from the researcher. Participants were allowed to speak at their own pace and address whatever aspect of the program they chose.

Each participant was interviewed once at the time of the final interview in the time series. Privacy was attained in all cases, however a second person (either the client's caregiver or the caregiver's client) was present during several of the interviews at the participant's request. The influence of their presence on interview content is not known. All interviews were conducted in person by the original researchers and/or their assistants and with permission were audio taped and transcribed verbatim; verbal consent was also obtained prior to the taped interviews (see Appendix C for study consent forms).

Data Analysis

Data, in the form of narrative text derived from transcribed interviews and field notes, was examined inductively using a thematic form of content analysis. Dyadic analysis was not attempted as the context of the study was to explore and understand participant's experiences in the day program rather than the relationship between clients and caregivers. Before data analysis was attempted, the researcher became immersed and very familiar with the data by reading the transcripts two or three times. Familiarity with data enables the researcher to recognize persistent words, phrases, themes, or concepts within the data and aids in the subsequent analysis (Field & Morse, 1985). As the transcripts were reviewed, impressions and ideas about each client or caregiver were recorded to develop a sense of the person. These profiles were extremely useful in maintaining a clear picture of each of the participants. Once familiarity was achieved, data analysis was initiated.

Once participant profiles were developed, transcripts were reviewed for key words or phrases that described the adult day program experience. Words with common meanings or major themes were grouped together into broad, descriptive categories. Each major category was assigned a code which was noted in the margin to help sort the data and uncover underlying meaning in the text. After data was classified and sorted into major categories, the information was examined closely for patterns, relationships, and more encompassing themes. The research questions provided a frame of reference from which the data was studied. The information sought related to the perceptions of clients regarding the day programs they attended and the impact the programs had on the process of managing their health. In addition, the perceptions of primary caregivers and the impact day program attendance had on the caregiving role was explored.

A code-recode process was utilized when examining the data for major categories and for themes. This was accomplished by examining the data for various categories and themes, then waiting a period of time and re-analyzing the same data to ensure that the themes and categories which emerged on re-analysis were also apparent initially. A major limitation of this study is that analysis occurred following data collection. Ideally, the phases of data collection and analysis take place simultaneously so that emerging themes and relationships serve to guide further data collection. Throughout the process of analysis, memoing was utilized to systematically record thoughts and ideas (Miles & Huberman, 1984). These notations were kept for reference in the later stages of analysis and proved invaluable in enabling the researcher to fully explore ideas.

Rigor

Qualitative methods are frequently criticized for failing to achieve reliability, validity, and objectivity; the criteria of rigor in quantitative designs. The purpose, goals, and philosophical underpinnings of qualitative methods are quite different from quantitative ones, consequently these criteria of rigor are inappropriately applied (LeCompte & Goetz, 1982). Guba (1981, quoted in Sandelowski, 1986) suggests that four factors may be used to assess the rigor of the qualitative investigation: truth value, applicability, consistency, and neutrality.

The first criterion of rigor is truth value or credibility. "The truth value of a qualitative investigation generally resides in the discovery of human phenomena or experiences as they are lived and perceived by subjects, rather than in the verification of a priori conceptions of those experiences" (Sandelowski, 1986). Credibility is achieved through faithful descriptions of participants' experiences and when people having that experience recognize it immediately from its description. In this study, the fundamental assumption underlying data collection is that participants know their world; this knowledge is truth, grounded in the reality of their experience. Direct quotes from participants are provided in the results to substantiate findings.

Another strategy that can be utilized to achieve credibility is the confirmation of descriptions and interpretations with study participants. Although the researcher was not able to validate her findings with participants, discussion of the data analysis with one of the original researchers was substituted to strengthen credibility. Additionally, journalling of personal thoughts and feelings is helpful to enhance self-knowledge. As the researcher is considered to be the major instrument in qualitative research, it is essential for him or her to be reflexive; that is the researcher is a part of the data rather than separate from it, and must learn to exploit self-awareness as a source of insight (Lipson, 1991). Careful reflection and systematic documentation of the psychological and emotional responses to the emerging data was utilized to provide a means of monitoring the research process.

Applicability occurs when study findings "fit" into contexts other than the actual study setting and when its intended audience views the findings as meaningful and applicable in terms of their own experience. The researcher's task is to present data which is grounded in the life experience of all participants and to include both typical and atypical elements (Sandelowski, 1986). To enhance applicability, every effort was made to describe the full range experiences represented and one of the original investigators was asked to comment on and verify the faithfulness of these descriptions.

Consistency is the third criterion of rigor, and is achieved when a study and its findings are auditable (Sandelowski, 1986). A clear, systematic description of methods or a "decision trail" allows for readers or auditors to follow the steps of a study and to arrive at comparable conclusions. Methodological, analytical and personal documentation was carefully recorded throughout the study as a means of auditing the research process and to ensure and substantiate the rigor of the investigation.

Neutrality, or the freedom from bias, can be achieved through self-knowledge of potentially biased thoughts and feelings. Again, memoing was utilized throughout the process to enhance neutrality.

Ethical Considerations

Both the original study and the present study were conducted in accordance with the regulations for ethical acceptability of the Faculty of Nursing of the University of Alberta. This researcher had access to the transcripts of the interviews which were stored carefully in a locked cabinet. Access was restricted to the researcher and her thesis committee. The researcher had no knowledge of the identity of the participants.

Chapter IV:

Findings

The purpose of this research was to describe the perceptions of clients regarding the day programs they attended and the impact those programs may have had on the process of managing their health. In addition, the perceptions of participant's primary caregivers and the impact day program attendance had on the caregiving role was explored. Content analysis of client's and caregiver's descriptions of their experience was completed to understand and interpret their perceptions, providing a rich description.

Study Sample

The sample for this study was comprised of eighteen day program clients and seventeen caregivers whose care recipient was attending a day program. Clients ranged in age from 42 to 83 years. Most were satisfied with their present community living arrangements and were supported by a family caregiver. Caregivers ranged in age from 33 to 82 years. The characteristics of clients are described in Table 1 and caregiver biographic information is presented in Table 2.

Table 1

Client Characteristics (n = 18)

Gender	
Male	10
Female	8
Marital Status	
Married	10
Widowed	7
Never married	1
Living Situation	
Lives with Spouse	10
Lives with Family	3
Lives Alone	5
Primary Informal Caregiver	
Spouse	10
Daughter	2
Daughter-in-law	1
Parent	1
None	4
Caregiver Frail	
No	11
Yes	3
Missing Information	4
Caregiver Health Problems	
No	9
Yes	5
Missing Information	4
Number of Days of Day Program Attendance/Week	
One	6
Two	11
Three	1

Table 2

Caregiver Characteristics (n = 17)

Age		
33-43	-	6
54-64	-	4
72-82	-	7
Gender		
Male	-	3
Female	-	14
Marital Status		
Married	-	14
Divorced	-	1
Common-Law	-	1
Never Married	-	1
Education		
Grades 7-9	-	2
Grades 10-12	-	10
Post-secondary	-	5

Program Description

Two models of adult day care were represented by the day program participants included in the study - day hospitals and day support programs. Day hospital programs focus more intensively on physical and rehabilitative needs while day support programs are organized to meet the socialization needs of clients and to provide respite for informal caregivers. Sample participants were selected purposively to represent the different programs, resulting in client and caregiver data from twelve sites.

Perceptions of Clients

Perceived Strengths of Programs

Overall, clients were highly satisfied and overwhelmingly positive about the day programs that they were involved with. They derived a great deal of enjoyment through their attendance and participation in program activities.

> It was wonderful! I enjoyed going more to the program than I did going to my daughter's.
>
> People would say - aren't you glad you're home? And I wasn't because I was beginning to enjoy it (the program) more and more all the time.
>
> . . . I would feel unhappy if somebody told me that there was a time where I would finish going to (the day program) because I would miss it so much. I look forward to it. And I'm grateful to my home care nurse that she approached me. Otherwise I would have missed out on a lot . . .

Specifically, clients identified a number of aspects of the programs that they enjoyed and were satisfied with: activities and services, program structure, relationships that developed with others and the effect that they felt the program was having on themselves and their family.

Activities and services such as recreational activities, the provision of information, nursing services, rehabilitation services and the opportunity to socialize with others were identified as beneficial aspects of the day programs that clients attended. Most days, there was a variety of recreational activities, such as games, crafts, trips and outings, exercise, music, videos, teas, etc. that the client had an opportunity to participate in. In addition to finding these activities enjoyable, clients were appreciative of these opportunities because in many cases it was a chance for them to be engaged in activities that they would not otherwise have had the chance to do.

> I enjoyed the day program. They gave you something to do every day you're there and they give you exercises which you don't normally take and they're really good.
>
> . . . a friend started telling me about his experience at the Lion's Club on Friday mornings and he told me about their playing bridge and that sort of thing . . . I have a very bad weakness for bridge. I love it and with the help of my card shuffler and my card stand I can play bridge really, really well so I thought if that's an opportunity for me to play bridge once a week, I would welcome that and I became very interested in the day care program . . .

Participants did not always enjoy all of the recreational activities offered, but in most cases were provided with more than one option for involvement.

> You can choose mostly what you want to do . . .
>
> They know I've got eyesight problems so they don't press me too much. If I want to do anything - I do - but if I don't feel like it, then they'll say - well, just take it easy.

They also recognized that whether or not they enjoyed the specific activity, if they did not take part in it they missed out on the opportunity for social interaction with others. Besides being enjoyable, participants perceived that recreational activities were beneficial to their functional abilities, intellectual functioning and overall health and well-being.

> . . . mostly what I enjoyed was the exercises. . . . we were doing these exercises and I really enjoyed them and they were making me feel good. I

> really felt good after the exercise. You know, you just felt like you could go . . . you know, just jump up and go but of course I couldn't.
>
> . . . it helps me to use my left hand, so bowling is a game but it's like an exercise too . . .

Effects of the day program will be discussed in detail in a subsequent section.

The provision of information to clients was identified as a beneficial service offered by adult day programs. Although educational seminars, workshops and printed materials were available to clients, they identified the informal sharing of information which occurs as program staff interact with them as being most valuable.

> . . . she's a wealth of knowledge. She's a smart lady and she can help me when I try to walk. She tells me how to put my foot . . .

Information about various health conditions, life skills, enhancing functional abilities and planning for the future were perceived as being most helpful in assisting people to cope with their present situation.

Within each day program, a multidisciplinary team of people is available to provide various services such as nursing, occupational and physical therapies, activity programming, social services, etc. The specific services offered and the personnel who deliver these services vary from program to program. Nursing services provided include the administration of medication, health assessments, counselling, health education, monitoring of specific illnesses, provision of specific treatments and assistance with activities of daily living. A few clients identified nursing services as a beneficial aspect of the day program. Specifically, the benefits of receiving health assessments on a regular basis, monitoring of specific illnesses and monitoring the effects and potential side effects of medications was viewed as important.

> . . . they had trouble getting my blood pressure down . . . so they used to take that twice a day . . . and they really tried to change the pills and decrease my blood pressure.
>
> . . . if you forget to take your pills or something, then you get heck. Which is what I most needed and that was what was the most beneficial because with my kids away from home they really didn't know what I was up to . . . it's been a great support for me.

The opportunity for the client to maintain or regain functional abilities through various rehabilitation programs was identified as a beneficial service offered by adult day programs. Three aspects of rehabilitation services were particularly helpful to people: instruction, support and encouragement, and the specific treatments they received. Instruction is provided through exercise classes and on a one to one basis.

> I like the exercise class the best. We all gather as a group and we have a good instructor who teaches us how to move all our limbs . . .
>
> (Client's wife speaking) One lady helps him get on his feet. She used to get in front of him and say "Come on now, stand up. Get your head up. Put your head right there on my shoulder." and so he did. He'd straighten right up and put his head right on her shoulder.

Clients believed that having a professional teach them how to move their bodies and how to compensate for any disabilities that they might have helped to keep them strong and healthy. Support and encouragement provided by program staff was also helpful in assisting clients to regain or maintain functional abilities and promote personal independence.

> . . . the doctor said "We can't do any more for you, but you've got to continue and you'll get stronger. You work that leg." So some nights I've

> been in a lot of pain and I've talked to my therapist . . . she said "You walk on that leg and it will feel better." Well, it has helped. I walk from the back of the house to the front of the house and my leg has felt better.

Actual treatments such as range of motion exercises, hot wax, and swimming were also perceived as being helpful to overall health and well being.

> . . . I was interested in what therapy I could get and I was surprised when I was told about the exercise program and the volunteers putting my left arm and my left leg through range of motion. That meant an awful lot to me.

One client was able to forget about his disabilities during his treatments which was a source of happiness for himself and his wife.

> (Client's wife speaking) The job (of the program) was the swimming and, of course, that relieved him from all pressures of his problem and he could forget that he had a problem in a pool which is really one of the most wonderful things for a Parkinson patient.

The opportunity for the client to socialize with others was identified as a key service offered by adult day programs. Many clients appreciated the chance to meet others and enjoyed spending time in conversation with them.

> . . . I enjoyed meeting the people that came there (to the day program) and you hear about what problems they have and that was very interesting . . . It's (the day program) given me a lot of encouragement because I like to meet people. I like to have friends. We have a great time talking about hunting or fishing . . .
>
> . . . the whole thing was that we were elderly people and we were discussing bygone days compared really to present days and we got quite a lot out of this.

> You meet all sorts of different people and some of these older people have great senses of humor so that you can laugh and enjoy yourself . . . it's an uplifting day when you go over there . . .

For a number of clients, outings were rare and the potential to become isolated socially was a very real threat. Coming to the day program became a link for them to other people.

> (Client's daughter speaking) It (the day program) gives her the chance to get out during the day and meet other people and not be just secluded in her own little apartment.

Clients identified the structure of day programs as a particular strength. The structure varied from program to program and in one case changed slightly during the original study's time frame. Although usually the day was planned with a variety of activities, "free" time was scheduled in as well, giving clients the opportunity to socialize with others or just simply to relax.

> (Client's wife speaking) . . . it's a full day out for him. It's not a program where he simply goes to a club. Every day they have an outing . . .
>
> . . . there are lots of times when we sit and talk together about things so you get to know them (other clients) this way.

Although the schedule was predetermined, it was not inflexible so it could be altered at times to meet individual needs. This consideration of individual needs and the freedom to choose what to participate in or whether to participate at all was identified as an important component of the program.

> (Client's daughter speaking) With mom what she likes best I think overall is the caregivers there sit with her one on one because she's not able to participate in other things because her sight is 20%. So they just talk and that's been very positive.

> . . . they seem to try to provide the needs that the individual has.

Clients were also highly satisfied with the day program staff. Staff were described as excellent, kind, considerate, helpful, smart, honest and concerned.

> The people there, they were kind and they were really honest people. They were concerned about every individual.
>
> . . . the nurses are so understanding. They help. Nothing seems too much for them to do . . .

Clients felt supported and respected by staff, adding to their sense of worth and belonging to the group.

> They treated all of their patients there with big respect and they were very considerate of each person there. Each member there was as important as the next.
>
> . . . it seems like they (day program staff) are there because they want to be there and not because they have a job to do. These people want to be there and it makes a big difference and they also provide a lot of support.

In a few instances, close relationships developed between clients and program staff.

> She (the program manager) really impressed me with the way she treated everyone and was very kind and very considerate and I became very close to her . . .
>
> (Client's daughter speaking) . . . the love and the caring for those clients goes much further than the monetary gain. The couple times when mom couldn't attend day care, K., on her own time, visited her, sent her cards, visited her with her dog. When mom was feeling really down, K. on her time off again, took mom to her place, gave her tea. That was their thing

> and there's a lot of love and there's a big bond there now because she went out of her way.

More commonly, relationships developed between clients. As a result of the time spent together and the sharing of common experiences, clients began to feel a sense of companionship and closeness with one another.

> I like best the feeling of comradery that we have. I look forward to that so much . . .
>
> . . . all the following week I look forward to my next time there (at the day program) with them. I know I'll have good fellowship. Even if there's some lonely times here at home I know I'm going to have some good fellowship there and good chats.
>
> . . . I got acquainted with one especially and her and I got quite friendly. . .
>
> . . . I just felt the warmth and the friendship and the affection . . .

Many clients spoke about the importance of the sense of belonging that was felt among group members.

> . . . it's (the day program) very important, especially for people who don't have family close. This is their only contact with other people. There's a sense of belonging . . .

This feeling of belonging helped some clients to feel less isolated. In addition to feeling as though they belonged, clients began to feel a sense of responsibility to others in the group. They became concerned about other people's welfare and assisted others in managing their health.

> . . . I tried to go out of my way to be friendly to other people. I talked with different ones because once you've been in the program you notice the ones that are left out . . . you can tell when there's a new person there and you see them sitting sometimes left alone . . . .

> We're just like one big happy family. If somebody gets hurt, you all feel . . .
>
> . . . they all look after my health.

Clients expressed immense satisfaction with these relationships and the fullness that they brought to their lives.

Finally, many clients reported being satisfied with day programs because of the beneficial effects they felt that they had both on themselves and on their caregivers.

> I was very happy with the results.
>
> I doubted whether it would do me any good, but it was quite effective.
>
> . . . it (the day program) gave her a little bit of time to be by herself without me there . . .

A few clients denied any effect of the day program whatsoever. Effects of the day programs on both clients and caregivers will be discussed in detail in a subsequent section.

Perceived Weaknesses of Programs

Although participants were highly satisfied and overwhelmingly positive about the programs they were involved with, several weaknesses and suggestions for improvement were identified. Clients were occasionally dissatisfied with characteristics of the program, program resources, accessibility, degree of control, treatment, program structure and specific activities within the program. One of the clients felt that the composition of the program needed attention in terms of the number of clients within the program as well as the gender of clients.

> . . . then they moved me to Tuesday and there wasn't so many men . . . maybe if they expanded (the program) a little bit that would help.

While participants were highly satisfied with the program overall, a few clients noted that programs were lacking in some resources such as staff, volunteers, education for volunteers and adequate space and materials.

> . . . nine times out of ten the places are so understaffed with regular trained people . . .
>
> They need a lot more volunteer people there.
>
> . . . they have a good program going but it needs to be enlarged probably a little bit and especially maybe they could get more people . . . It needs a little bit more accumulation of materials and things.

Despite this noted lack of resources, clients were very pleased with the programs and the level and quality of care that they received.

Several of the clients identified lack of access to day programs as a significant barrier and a source of dissatisfaction. A number of factors such as cost, transportation, and distance from day programs appear to limit access. The cost of administering day programs including rent, salaries, equipment, supplies and miscellaneous items is variable. For most adult day programs in the study, government funding accounted for a substantial portion of the funding for program operation. Other sources of income included donations by individuals or organizations, associated institutions and client fees. Most of the day programs charged a daily program fee for clients to help offset the costs. In some cases, this fee includes meals or transportation, or both. Daily client fees for the program included in this study ranged from a low of no charge to a high of $10.00 a day including all costs or $9.00 a day plus transportation costs. Although costs are negligible in most cases, they may be unmanageable for some people.

> (Client's husband speaking) . . . although it doesn't cost much to go to the program, it can be a lot given your financial circumstances.

Another client and his wife worried a lot about their finances as they had immigrated a few years ago and did not have full coverage of their health expenses. Although they were managing well at present, they were concerned about what could happen to them if their circumstances would change - for instance if the client's wife became ill and could no longer care for him. Thus, the minimal cost of the day program was a source of anxiety for this couple.

Transportation to the day program also presented difficulty for some people. Many of the programs had arranged transportation to ferry clients to and from the program. Until that was in place, however, clients had to make their own arrangements. Even when transportation was provided, people could not always rely on it to be reliable or prompt depending on demand.

> . . . the DATS will pick you up and bring you back but they won't guarantee you they'll pick you up at say two-thirty. They'll say, well, we will if we can. If we can't, then we'll pick you up at four or something.

For a few clients, the distance required to travel to attend the day program was a significant barrier and in some cases prevented people from attending the program. This was particularly evident for those living in rural areas.

> . . . it was such a distance for us being so far from L. it was not feasible . . .

In some of the rural areas, transportation was arranged so that clients were not required to organize their delivery to and from the program. Although this did make it somewhat easier for clients to attend the day program, distance and the time required for travel remained problematic for some.

> I could complain a little bit about the bus I guess. That road has pot-holes bad so it's a little bit rough . . . when you are sitting a long time you feel it more.

For elderly clients already somewhat frail, travel alone could be exhausting.

A few of the participants felt that they had not been involved enough either in the decision to attend the day program initially or in subsequent decisions about the structure of the program they had already been attending. One caregiver described how this affected her mother:

> . . . some of them they feel a bit like my mom where it really wasn't their choice to go to this (the day program) but it's becoming an accepted situation now and maybe it would be more positive if the client . . . had known of this program themselves. . . . it's the point of telling you that this is where you should go, it doesn't make them feel in control anymore and I know for mom it bothered her a bit for someone to say "I think you would benefit and you should go."

One client, who was initially unwilling to attend the day program, was brought there on the pretense of "going shopping." Although she subsequently came to enjoy the program, she remained resentful of the tactics that were used to convince her of this as well as the people who used them.

> I lived my life long and I didn't want to go . . . I no like it that she pushing me there . . .

A few participants identified lack of input into decisions, especially decisions regarding changes to the established structure of day programs, as a source of dissatisfaction.

> They changed the opening of the day. Instead of having coffee and toast and a little time for chit chat, they changed that all around. No coffee at all. They started right with the program and then they served coffee at ten thirty. Well, that didn't suit me at all.
>
> (Client's wife speaking) . . . when this started to change they were told what to do and when to do it and it was bang, bing, bing . . .

Although clients were highly satisfied with day program staff and the quality of care that they received, a few participants were dissatisfied with certain aspects of their treatment. In most cases, staff affirmed the worth and self-dignity of clients, but occasionally clients felt as though they were not treated with respect. Two clients felt that they were treated as though they were children.

> . . . sometimes I did feel that I was being treated like it was a glorified baby-sitting service . . . Maybe I was expecting more out of it in the sense that you could socialize with these counsellors . . .
>
> . . . they treat me like a baby.

Another client needed support and encouragement for the positive health habits she displayed rather than having her shortcomings discussed by staff.

> (Client's daughter speaking) I think that if they would give her credit for what she is doing instead of the negative feedback for what she's not doing might help . . . if they start putting her down too much, then it gets her in such a tizzy and then she starts feeling physically ill over it and it gets her very stressed so that's a concern.

Although most participants identified the structure of day programs as a particular strength, a few people felt that it was either too structured or too flexible.

> (Client's wife speaking) . . . He really, really missed (the time to socialize). It could even be . . . something like having verbal conversations with the other clients while you are busy with your hands, but that was never there. It was always now you are going to do this, now you are going to do that and so they always kind of sat there and did what they had to do . . .

> . . . there were times when I felt that maybe it could have been organized a little better, a little more structured because there were lots of times when we were in between activities . . .

Several participants identified specific activities within the program that were a source of dissatisfaction. They either disliked some of the activities that were offered, or they felt that the activities they would have liked to be engaged in were lacking.

> . . . I felt that some of the things didn't apply to me . . .
>
> (Client's wife speaking) He didn't like the exercise part of the program at all. He wouldn't even participate in it.
>
> . . . they had a Relaxation group and I just went once and I didn't like it because I couldn't relax . . . and I said I would rather do that at home.
>
> The days were so well planned, every hour we were supposed to do certain things and I reminded them - but I came to play bridge and when are we going to play bridge? Well, that was a lower priority as far as they were concerned . . .
>
> (Client's wife speaking) What was really missing in the program is that there was no sharing time amongst them, for them each to express how life has changed and I think that's really important for your well being.

In most cases, the wide variety of activities and options for choices enabled people to be involved in activities they enjoyed. However, one client was contemplating leaving the program because the activity he desired was no longer offered consistently.

Overall, clients were highly satisfied with day programs and derived a great deal of enjoyment and benefit through their attendance and participation. The strengths and benefits identified as most important include activities and services, program structure, relationships with others, and the effect that clients noted on themselves and their caregivers. Most of client's dissatisfaction and suggestions for improvement centered on the issue of accessibility particularly the cost of the program and the need for a reliable, cheap form of transportation to be provided.

Perceptions of Caregivers

Caregiving Situation

As well as describing their perceptions of the day program, caregivers discussed their situations and the demands that caring for their loved one placed on them. Although it was not possible to determine from the data the length of time that all caregivers had been in that role (over 30 years in one case), becoming a caregiver was described as an unexpected occurrence. Caregivers felt unprepared for assuming the caregiving role and did not always feel that they had the necessary assistance and support.

> You just sort of fall into everything . . . you're just kind of walking around blindly like OK . . . what's the next step . . . She's burning stuff in the microwave. I guess we'd better find another solution to that problem.
>
> I often thought about I wasn't prepared for taking care of my mother at all and I had no idea. I thought they were just going to be fine and one day they would just be gone and that would be it. You don't realize that there can be that in between . . .

The types of care provided by caregivers varied from minimal assistance with shopping, cooking and home maintenance to total care of activities of daily living. Three categories of care emerged from the descriptions: anticipation of needs, hands-on caregiving and protection. Anticipation of needs includes activities carried out for the purpose of preventing illness, injury or complications of existing conditions. It requires the caregiver to be very vigilant and tuned in to monitoring the health status and needs of their loved one.

> . . . he comes home and curls up in his chair and I have to tell him to put the legs up because he's having a little trouble with fluid retention . . .
>
> . . . when I leave now I have to line everything up because he is not capable of walking from the bedroom or getting from the bedroom to the kitchen so that my being able to leave for a couple hours, there's all this pre-arranging . . .

Hands-on caregiving includes all the tasks that caregivers do for or assist their loved ones with such as bathing, dressing, eating, etc.

> Well, I have to do everything. Bath her . . . I have to dress her and, well, I do everything, wash clothes, make the beds, clean up, wash pots, make her meals and it's a full-time job . . .
>
> I have to change his diapers and give him a bath and brush his teeth . . .

Protection refers to activities that protect the self-image of the person being cared for. Caregivers protect their loved ones from an awareness of the significance of events and from the awareness that they are being "cared for."

> . . . you don't want to take any dignity away from your parent because obviously they are deteriorating and, you know, it's not much fun for them and it's not much fun to watch either. But at the same time you're taking things over slowly because they can't handle them anymore and it's very difficult sometimes to know when to take things over and when not to. For the longest time mom did her own bills but I could see her just struggling, you know, with four measly little bills and it would take her an hour. She'd be going over and over and over again these bills and it was like, it would take me ten minutes . . . and it's hard to know when to take

> over and when not to because you don't want them to lose their dignity but at the same time, you know, you realize that they can't handle it anymore.

One caregiver described a situation where her husband would get lost in the town where they had lived for many years and ask for directions from friends. The caregiver protected her husband, neutralizing the significance of the situation by attributing its cause to something less disturbing than the real cause.

As caregivers described their caregiving situation, they discussed what it was like to care for someone and what demands the caring placed on them. All caregivers expressed a need for support or for some type of respite service.

> . . . I left her back east in a home and then flew back, picked her up and then all of a sudden I was by myself. I'm alone with her for two weeks at least . . . I'm surprised I survived it . . . it was very stressful. The first little while just about drove me nuts because I had nobody to, everything wasn't in place yet in terms of help or volunteers or home care. For some reason they automatically assume because you are at home you can take care of this person on a full-time basis and you can't. You can't do it 24 hours. You'd go absolutely snaky . . .

Their responses can be classified into three categories: demands on time, physical burden, and emotional burden.

Caregivers described the burden that was placed on them due to restrictions on their time. They spend a great deal of time and energy assisting the care receiver with daily tasks and basic functions.

> You are on 24-hour call because they get to be very demanding and they won't do anything for themselves.

The constant vigilance and unrelenting nature of the caregiving situation is particularly stressful for people.

> . . . it's not her (caregiver's wife) really but I don't get a rest. If I sat down, will you get me some water? Two minutes later, will you get me some water? And that goes on day after day . . .

Because of the enormous time demands, caregivers often neglected their own needs, wants and desires.

> . . . I had been taking care of mom for about two years and had given up my career to take care of her.
>
> I've never been busier in my life with little things. I don't have the time to do a lot of the things that I used to do . . .

In addition to the enormous time demands, caregivers described their feelings of fatigue and risk of damage to their physical health because of their caregiving role.

> . . . during the night I've got to get up because she has to go to the toilet. We've been up as many as five, six times in a night and then I can't go to sleep because I'm wide awake . . . then she expects me to get up early . . .
>
> . . . it's becoming very, very stressful and it definitely has shown on my own health . . .
>
> . . . I'm going to the doctors and being told well, you are killing yourself with stress and hypertension and the whole bit plus my blood pressure zooming and I need to go for surgery but I can't go for surgery . . . I can't come back in a weakened condition to try to survive in this tension-filled situation. There's just no way.

The caregiving role was also described as being very difficult emotionally as caregivers struggle to cope with the emotions that arise through their role.

Most caregivers found it hard to accept the changes in their loved one and were saddened over their increased dependency.

> . . . he does not remember things. He watches TV but he couldn't tell you what he saw on TV. . . . it makes me feel sad . . .
>
> . . . she wasn't quite the mom I had grown up with . . . she was totally dependent on me like a child and it's difficult to see your parent go that way especially with my upcoming wedding I really wanted her to be involved, but she couldn't do that anymore . . .
>
> In the last eight years, I've seen her go from a woman who could do everything including cooking and washing to a woman who was totally dependent on me and could hardly even walk in the end or think for herself or anything . . .

Some caregivers found it difficult to be able to relax because of the need to be continually monitoring the needs of the care recipient.

> . . . your mind is always tuned in with, well, now let's see. It's been two hours since he had some water. I wonder if he'd like a glass of water, or milk, or all these kinds of things. Your mind is always tuned in to their needs . . .

For some caregivers, the behavior of their loved one resulted in feelings of pain, resentment or embarrassment.

> . . . he (caregiver's husband) looked at D. and he said "By the way, how are your parents?" and here they've both been dead for years. . . . a knife jabs right through you because they look so shocked . . .

Concern for the safety of the care recipient was identified as a significant stressor for caregivers, adding to emotional burden but also restricting the social activities of the caregiver.

> . . . I'm loathe to leave her because the number of times she's got up while I've been out and fallen . . . she's always been active and now she's an invalid and can't walk . . . when I go out I'm all on edge about what's happening when I come back. If I find her on the floor . . .

Perceived Strengths of Programs

Overall, caregivers were highly satisfied and overwhelmingly positive about the day programs that their care recipient attended. They were particularly satisfied with the wide range of activities and services that were offered within the program and the effect that they felt the program was having on themselves and the client. Activities and services such as recreational activities, the provision of information, nursing services, and rehabilitation services were identified as beneficial aspects of the day programs. Recreational activities were seen as providing the client with an opportunity to have fun and enjoy life.

> The day program provides such a range of experiences for these people. Bowling, music, painting, water colors, dances at the over 50's center. My uncle loves the dances, the bowling, the indoor games. He's very good at games, things that he's never had the opportunity to do in his whole life. He was a farmer that worked very hard, had very little time to do recreational things.
>
> . . . he was not outgoing so he never was involved in the fun things of life and now he's having fun and he comes out of there and he says "I had such fun today" and before this, I had never associated the word fun with him. I didn't think this man ever enjoyed the good things in life and now he is. This is the very first time and he's 80 years old.
>
> . . . it's a fun day out so to speak. He really enjoys it and they are telling me that he's opening up.

> . . . they started a swimming program and that was the one thing that he really thoroughly enjoyed. He looked forward to going.

The provision of information was identified as a beneficial service to caregivers. They noted that there was a general lack of information and education materials available to them regarding aging, particular illnesses, and how to manage with the demands of caring and were grateful for the education provided through the day program.

> . . . I really was grasping at straws when I first started taking care of mom. It was like where do I start? What do I do? Who do I go to?

Information was supplied formally through seminars, workshops and printed pamphlets, but education also occurred informally as program staff interacted with clients and caregivers. Several caregivers identified nursing services as a beneficial aspect of the day programs. Specifically, the benefits of the client receiving quality care and careful assessments and monitoring was viewed as important.

> . . . They (day program staff) take exceptional care of them.
>
> . . . I was completely comfortable with his going (to the day program) because I knew he would be well taken care of . . .

Caregivers were also very appreciative of the rehabilitation activities which assisted their care recipients in maintaining or regaining functional abilities.

> . . . they get their exercise component because they do go to places where they have to go for a little bit of a walk and they go on lots of walks around the parks . . .
>
> . . . she gets her exercises that I can't always give her which I try to do.

Finally, all caregivers reported being satisfied with day programs because of the beneficial effects they felt that they had both on themselves and their care recipient. Perceived effects of the day programs on both clients and caregivers will be discussed in detail in a subsequent section.

Perceived Weaknesses of Programs

Although the majority of participants were highly satisfied and overwhelmingly positive about the programs they were involved with, several weaknesses and suggestions for improvement were identified. Caregivers were occasionally dissatisfied with characteristics of the program and accessibility.

A couple of caregivers felt that the composition of the program needed attention in terms of the age and gender of clients. One caregiver believed that the program focused too closely on the needs of the elderly person and that the view should be broadened to encompass younger people as well.

> I don't see why they are so concerned and dwelling so much on just the elderly. Yes, the elderly do need this program but so do this other age group of people also.

Another caregiver agreed; she felt as though her sister was left out somewhat because of her young age.

> It seems as though my sister is one of the youngest going to this program and they seem to dwell on that with her . . . that this isn't a program for young people . . . her age is only 43 but its something that's definitely needed for her because there's nothing out there.

Most of the caregivers identified lack of access to day programs as a significant barrier and a source of dissatisfaction. Transportation difficulties, hours of operation and program space appear to limit access to caregivers and clients. Transportation to the day program was not provided in all cases which meant that the caregiver had to use some of their "free" time to drive the client to and from the program.

> . . . in the beginning they didn't have the transportation worked out so I was running her into H. and back so that's four trips . . . especially if that's the only time in the week you really get a chance to kind of go and get your grocery shopping and your bills paid.

For caregivers who work, the transportation arrangement posed unique difficulties. Not only did they rely on the driver to ensure their loved one travelled safely, but in some cases drivers assisted clients out of their home, helped them lock up, etc. One caregiver worried about the safety of her home as well as that of her father.

> . . . handi-bus drivers come and go and I don't really know that I trust somebody to come to the door and lock the door behind him and take him to where he's going and bring him home and open up the door for him, that kind of stuff.

The number of hours and days of operation per week varied from program to program. Typically, however, programs operate during the week (Monday to Friday) and during the day (from 4.9 to 8.2 hours per day). Several caregivers noted that the caregiving role encompasses 24 hours per day, 7 days per week and that access to the day program during "off" hours would be beneficial to them, allowing them the opportunity to engage in usual social activities and events.

> Maybe if they had hours like eleven to six where you have a whole afternoon to go out and visit friends or go shopping . . .
>
> Like a Saturday or a Friday night would have been nice . . .

Caregivers stressed the fact that they were not asking for extraordinary services, but wanted respite so they could be involved in normal, usual activities that most of us take for granted.

> . . . it would be nice if they had more entertainment like in the evenings which would give the caretaker a chance to go out on their own . . . especially if they are able and well-bodied, then they'd want to go out and do something else. Like they might even want to just go bowling . . . it doesn't have to be stupendous . . .

Because of the lack of extended program hours, caregivers were forced to make their own arrangements for replacing themselves when they needed some relief from the demands of caring or when they wished to participate in activities. Making alternative arrangements was not always an easy task.

> I wish the day program was open once in a while in the evening so I could at least get out once a week to my Bible Study or whatever it was . . . Everybody wants to do a few things in the evenings. Eventually we found an older lady herself who is retired and living alone so she would come in and watch mom for me.
>
> . . . I would yell at mom much like you would, I guess, if you had a child. You'd be upset or frustrated because you couldn't get out and yeah, it's a little harder to find a sitter for an elderly person. It's not like phoning up the next door neighbour's kid and seeing if they can sit while you get out, even just to get groceries.

The expansion of hours is particularly important in supporting those caregivers with other demands on their time such as work. Because the day program hours coincide with usual working hours, intended caregiver outcomes such as respite from the demands of caregiving are not evident.

> The day program hasn't changed much for me really . . . It's not as though I'm a caregiver that's at home Monday through Friday and then when he

> goes to the club on Monday's, it's not like a day off for myself because I'm at work anyway so there hasn't been many changes that way . . .

Limited availability of space within the day programs was identified as a source of dissatisfaction by all caregivers. Although all clients were attending the programs at least one day a week, many of them would have attended more frequently had that option been available to them as the program was believed to be extremely beneficial.

> The one thing that would be very helpful for him would be to be able to go three times a week rather than two times a week.
>
> I wish it was maybe twice a week instead of once, only once. Give her more chance to go out especially in the winter time. In the summer time it's a little easier to take her out.
>
> . . . she was only enrolled two days a week because that was the only time left for her and had there been more days we would have asked her to be enrolled for more days.

Caregivers were also highly satisfied with the day programs that their care recipient was involved in. Most important to them was the wide variety of activities and services offered to themselves and the clients and the effect that caregivers noted on themselves and their care recipient. A major source of dissatisfaction identified was the lack of accessibility especially transportation difficulties, limited hours of operation and limited program space.

Perceived Effects of Day Programs

On Clients

Clients and caregivers were asked to describe what effect the day program has had on their lives, as well as on the lives of their family and friends. Although for the vast majority of clients and caregivers the day program was perceived as being enormously beneficial, three respondents felt that the program had no effect whatsoever. For the remainder, responses to this question can be categorized into the following: effect on functional abilities, effect on health, delay of institutionalization, effect on intellectual functioning, and psychological effect.

> (Client's wife speaking) . . . when he's happy, when he comes out of there (the day program) feeling so good about himself, it gives me a good feeling and I find that if I feel good my whole day goes a lot better. I really think it's an important thing for me as well as it is for him.
>
> (Client's daughter speaking) . . . it (the day program) gives such a fullness to their life. I think that after a person retires or quits a job and they haven't got anything to do, that they lose something. They lose a purpose. They lose out in why they should even be around . . . if they have a program like this to go to it just provides a fuller life . . .

For many clients, rehabilitation activities and exercises were important services provided by the day program even though most reported no change in their functional abilities. Two clients did describe an improvement in function, while no one described a deterioration.

> . . . my one leg is quite useless and they told me that they could strengthen that so I could walk to get around. I had my doubts, but actually it was quite effective. I have to say that it was so effective that I was able to get around with a walker instead of by wheelchair.

The improvement in this client's mobility enabled him to get around within his own home more easily, to drive his car again and to attend public functions.

> . . . right now I can go out with the assistance of my wife in the wheelchair and, well, go to church sometimes which I never thought I would be able to do.

Another client with a weakened leg was able to strengthen the leg and improve her mobility to the point where she could walk from the front of the house to the back, enhancing her independence.

Several clients reported a direct health benefit as a result of attending the day program and engaging in some of the activities and exercises. One client's blood pressure was well controlled and her gout was less problematic to her since she started swimming regularly at the program. Others mentioned more general benefits such as simply feeling better or more energetic.

> I really have a whole lot more energy than I did in the past . . . I can eat a little better and I can sleep better and walk a little faster . . .
>
> . . . we were doing these exercises and I really enjoyed them and they were making me feel good . . . . You know, you just feel like you could just jump up and go . . .

A few clients and caregivers discussed the importance of home and of their independence and the role that day programs played in enabling them to remain at home.

> (Client's daughter speaking) . . . I do hope the government realizes . . . that it (the day program) does keep a lot of them (day program clients) out of extended facilities . . . . If mom didn't have all her ongoing care and support she would be one who would need that type of facility too.

One caregiver saw the day program as one point in the progression from independence to dependence and institutionalization. Although she saw the progression as inevitable, she attributed the day program with supporting her husband's community living arrangement for a period of time before institutionalization became necessary.

> (Client's wife speaking) . . . he was here (at the day program) for two years, and you know, I don't know that we could have made it that far without programs like this . . .

Several caregivers were committed to the caregiving role, indicating that they wanted to be able to care for their loved ones at home for as long as possible. Day programs were viewed as supports in assisting them in achieving this goal.

> (Client's daughter speaking) You are going from meals on wheels and leaving her home alone to eventually a day care program and eventually a nursing home and that sort of thing. I tried to keep her out of the nursing home for as long as possible but yet there comes a point in time when you just can't.
>
> (Client's daughter speaking) . . . I think if you put someone in a day care program, that's basically what you're saying is I'm just not ready to put her in that nursing home yet and yes, it will come but I guess you're trying to hang on to them for as long as you can.

One client and several caregivers reported an improved intellectual functioning which they attributed to the stimulation of conversation and games such as Bingo.

> (Client's husband speaking) You could tell because when she hadn't been (to the day program), then we had no conversation . . . As soon as she's been to day care, we have a conversation. She mentions the nurses' names and she has a conversation about it . . . which I think is a good thing because she's not just got a blank mind then. Her mind is working . . .

Other caregivers noted that the client was able to engage in conversation more readily after the stimulation of the day program.

> (Client's daughter speaking) . . . it benefits her quite a bit. I feel she's more responsive than she was before. We have things to talk about . . . She comes home with quite a bit to say usually even if its about someone beside her.
>
> (Client's husband speaking) . . . she meets people which is a great thing and when she comes back and I start to talk to her and ask her what she's been doing and she repeats everything . . . it's getting her to talk to me more because if we're in together, then you run out of conversation.

Several other caregivers described an increased alertness and awareness. One client performed better on mental function tests than he had previously.

> (Client's wife speaking) . . . the amazing thing was the tests or the games or whatever they did this morning, he did better on them than he did a year ago when the doctor tested him so whether it's the stimulation of being able to talk to these men or whether it's the exercises or the word games or the little games they are playing, I don't know what it is but it's triggering something.

By far the most frequently reported effect was psychological. Clients and their caregivers noted improvements in mood, responsiveness and in social relationships. Clients were described as happier, more interested, more confident, more socially outgoing, initiating conversations more frequently, more refreshed and involved and more responsive as a result of day program attendance.

> (Client's daughter speaking) . . . he's like in a much better mood when he comes home . . . you can tell when he comes home from the club (the day program) that he's had that stimulation all day.
>
> (Client's wife speaking) He's initiating conversations now whereas before he just kind of gave feedback . . .
>
> (Client's niece speaking) . . . she felt good about it (the day program) because she was getting out and meeting people . . . she herself was feeling good and it has been building her confidence . . .

Two of the caregivers also reported that the person had less complaints and did not require as much attention on days when they had been to the day program. In addition to these general psychological effects, participants also noticed a sense of meaning in their lives, an expanded world, a sense of belonging and gratitude for what they have in their lives.

For several clients and their caregivers, day programs were seen as important in providing clients with a sense of purpose or meaning in their lives. For some, the program brought meaning by simply giving people "something to do" other than being at home. The alternative for many of the clients was being alone; sitting around passing time.

> (Client's daughter speaking) . . . the time she had at the adult day program, I think, was very important because I think it kept her going. It kept her going for a little bit longer . . . so at least she wasn't just sitting here or sitting in a nursing home kind of wondering when somebody was going to pay attention to her.
>
> I go to the day care on the south side here, just a place, something to do.
>
> (Client's daughter speaking) . . . his only alternative to that (the day program) because we work all day and there isn't anybody here to do

> anything with him or take him anywhere, his only alternative to that is to just kind of sit around the house all day.

Even on days when the client was not attending the program, the anticipation of the next visit provided meaning by giving the person something to think about and look forward to.

> (Client's daughter speaking) . . . without the program she wouldn't have anything to look forward to. She wouldn't really have anywhere to go. She needs to have the program in order to have something to look forward to and something to get out of bed for each day.

While for some clients the day program was simply "something to do" other than being at home, others felt a sense of achievement or accomplishment through the activities they were involved in at the program.

> (Client's daughter speaking) . . . I'm sure that she felt needed there because they made it out that she was working, that she was doing a job. She wrote to the relatives and told them that she was working at the hospital, that it was volunteer work that she was doing . . .
>
> (Client's daughter speaking) . . . the other people are dancing but his important job is keeping time to the music so to help the people dance better and he thinks that's great. . . . It (the day program) provides fun, excitement. It provides so many things to a person with a dull life.

One woman's "job" was to interview the other client's about their past. Not only did this provide a sense of achievement for her, but the clients she interviewed felt valued and involved.

> . . . it's wonderful that they've finally recognized that they are special people and that they have something to contribute . . . it's quite a relief for them to . . . be able to talk to people.

For several clients, the sense of meaning resulted from helping others in the group. Assisting others helped to validate their importance of value within the group and provided clients with a feeling of personal satisfaction.

> . . . I have an occasional chance to lend a helping hand to somebody who is more disabled than I am. It always makes me feel good.

One client paid particular attention to those who were new to the group or isolated. She made it her role to ensure that all members felt welcomed and wanted.

> . . . I always make a point of going over and introducing myself and sitting there having a little chat for a while. . . . I can't really actively do anything to help. But I can help by offering my friendship.

For many clients and caregivers, day programs were viewed as important in providing clients with a change in their daily routine and in broadening their world. The change provided a break in an otherwise monotonous routine and exposed the client to new people, new activities, and new ideas.

> (Client's wife speaking) . . . we both looked forward to this five hours that was a complete change. But here was five hours out of that seven days where we both had a complete change . . . it was the only five hours in that seven days a week whereby we were doing something separately.
>
> (Client's wife speaking) . . . his world was a little bigger. He had contact with some other persons.
>
> It was a way to spend time, away from home. An outing; a change of scenery.
>
> (Client's daughter speaking) . . . I think it's been really good. It gives her a chance to get out during the day and meet other people and not be just secluded in her own little apartment.

The change in daily routine provided clients and caregivers with something to talk to one another about.

> (Client's wife speaking) He could come home and tell me about a bridge hand and somebody saw this and he met somebody from so and so and such and such . . . . And without my being there we both had something different to tell one another. We weren't together whereby now we have nothing to tell one another because we are together when it happens.

One caregiver emphasized that if it were not for the day program, his wife would have spent the entire winter at home because it is too difficult for him to take her for outings in her wheelchair.

The feeling of belonging and a sense of commitment to others within the group was viewed as an important benefit to clients of attending day programs. Because some past involvements such as jobs and group memberships are discontinued, some elderly felt isolated and uninvolved with others. The day program became an important link back into the community.

> . . . People need to get out. Once you're not able to get out in society, you know, functioning work-wise or whatever, I think it's a real need to get out and socialize with other people and sometimes just verbally sharing has a lot to offer . . .
>
> (Client's daughter speaking) . . . they have a sense of belonging again in society and I think that's important.
>
> . . . It (the day program) lets you know that we're not alone, we need somebody else for help. We need friendship. We need help.

Group members began to care about one another and play a role in monitoring each other's health and happiness.

> . . . something was bothering her and she got to the stage where you could tell by the way she came in the last couple of times that I saw her. She was sort of sliding back because she became very, very quiet, wasn't quite as sharply dressed as she could be . . . something was bothering her.

In addition to monitoring one another's health and happiness, clients began to feel a responsibility to others in the group. Because they were aware that others were relying on them or would miss them if they weren't present, clients felt a sense of commitment to attend and to share in the lives of others.

> (Client's daughter speaking) . . . I think they all feel they need to be present. The one day mom was ill she still went in late. She felt she had to be there because another person would miss her so it was really positive . . .

Through attendance at the day programs, clients began to feel grateful for what they had in their own lives. This sense of gratitude resulted from the comparison to others perceived as less fortunate than themselves.

> . . . it (the day program) was enlightening. It was in talking to them (other people in the program) you realized how fortunate you are yourself because I know that some of those people were living on fixed incomes, small fixed incomes.
>
> . . . when we work with handicapped we find out how lucky we are . . . people that have no arms and legs, how do they get around? I wish more people would see it. We always complain how bad you are off.
>
> . . . I enjoyed meeting the people that came there (to the day program) and you hear about what problems they have . . . that was very interesting too because you don't realize how well off you are . . .

Overall, the day program was perceived as being enormously beneficial to clients. Improvements were noted in some clients in functional abilities, general health and intellectual functioning. Most clients were happier, more interested and confident, and more socially outgoing. The day programs were viewed as providing clients with meaning in their lives, with broadening their world and a sense of belonging to a larger community. The overall result of improvements in these various areas of the person's life is an enhanced quality of life as the individual retains a sense of dignity and independence, an increased freedom from loneliness and the continuation of meaningful relationships.

On Caregivers

In describing the impact that the day program had on them, caregivers identified support, peace of mind and respite as significant effects of the program. Several of the caregivers attended the support group and identified it as being important in assisting them to cope with their situation. Caregivers felt supported by hearing the stories of people in similar situations and by recognizing that they were not alone.

> . . . the program has given me an insight of how people are trying to help and it makes me feel better . . . when we were younger we were both quite active and it's kind of tough at times to think that you've got to carry on. But I know these sessions have given me a different outlook on the way people are trying to help us . . .
>
> . . . the support group helps those that are caregivers and that helps a lot and it was like the lady said that it helps just to know that other people are, that you can share things because unless you've lived through it . . .

Caregivers were welcomed to take part in activities at any time and felt support by staff and other caregivers they met under these circumstances as well.

> . . . it (the day program) helped us meet and get new and different friends and we need them at this stage.

Peace of mind or relief from worry and responsibility was identified as a significant effect of the day program. For some caregivers, this peace of mind resulted because of the effects that they detected in their loved ones.

> . . . for me it's much easier when he finds life easier, when he's happy, when he comes out of there feeling so good about himself, it gives me a good feeling and I find that if I feel good my whole day goes a lot better. I really think it's an important thing for me as well as it is for him.

A few caregivers identified the relief of responsibility from caring as being significant to them. The time that the client is at the day program is really the only time that many caregivers are able to let go of their responsibilities temporarily and think of themselves instead.

> . . . it's really good for the person attending as well as the caregiver because of the freedom it gives the caregiver to not be responsible for them at those times . . .

> . . . it did give me that break and sort of the relief of knowing that somebody is taking care of her. I don't have to worry about leaving her. I can go get something else done or do something else. I have some free time to myself and that was very important to me.

For other caregivers, peace of mind resulted because of the faith they placed on the quality of the program and services. It was important to caregivers that the care recipients be left with someone who is competent and caring, and that the client enjoy and benefit from the program.

> I do think with the day program it's going to give me a break. I know where she will be and I know that she will be with good company and I

> know that I've not just sent her there. I've been down to have a look and I find that the nurses and the therapists, they're great people and they care. I know when she's there my mind is at rest. I know she's in good hands and she appreciates it and so do I.

> . . . it gives you time off and knowing that they are cared for plus they are being observed for evaluation . . .

In addition to the quality of the program and services provided, many caregivers viewed the day program as being a safe place for their loved one to be. The knowledge that the client would be safe and secure helped to relieve them from the responsibilities and worries of caring.

> . . . the thought of not having to worry about where he was or that he's in a safe place for that many hours . . .

> . . . you're planning for those special hours of well, of relief because you don't have to worry about where he is and go do your own thing and you know he is in a safe place . . .

> . . . she only went the two days a week because that was the only time slot but you knew that she was safe and you knew that you weren't going to get all those phone calls all day long or that she was going to wander out of her place.

When describing the impact that the day program had on them, all caregivers identified respite or freedom from the demands of caregiving as a significant effect.

> . . . it's given us a lot more freedom. That's how it's changed our lives basically because now he's gone two full days a week so it gives us a lot more freedom to do things and that's probably what I like best about it.

> . . . it's absolutely marvelous for both people, not to have to spend 24 hours a day, 365 days a year in one another's presence. Under no circumstances in life will one do that with another single person. You'd be upset or frustrated because you couldn't get out and yeah, it's a little harder to find a sitter for an elderly person. It's not like phoning up the next door neighbor's kid and seeing if they can sit while you go out for a walk or even just to get groceries. It was just a very frustrating time for me and this (the day program) gave me the break I needed even though it was short because she was only going twice a week.

Not only were caregivers released from the demands of caregiving during the period their care recipient attended the day program, but they had time for themselves. The idea of having their own time to do with what they wished was extremely important to caregivers.

> Just the idea of having an evening to yourself that you didn't have to worry or jump up and down a million times for the person that you are looking after that they want this and they want that . . .
>
> Now this may sound so silly but to be able to know that for five hours you can do exactly what you want to do when you want to do it. . . . for five hours you didn't have to be tuned into anything but yourself.
>
> . . . it (the day program) made my life better. It was a wonderful thing that gave me Thursday afternoons free that I could go and have lunch with a friend and I also went for afternoon tea with another friend who had had surgery and this is something I just couldn't have done if he had been home and another time I stayed home all day and read a book and wrote letters so this was really a wonderful day for me because I could do just as I wanted and I didn't have to wait on anybody . . .

In a couple of cases, the respite provided by the day program was insufficient to meet the needs of caregivers.

> You're just like zoom, you know. I've got to get into town, get this done, get back, you know and yeah, it, I still didn't have any free time so to speak to myself to sit back and relax. It was like this is my chance. She's out of the house. I can do the vacuuming or whatever, you know, because sometimes you just couldn't get that done when she was here . . .

In addition to these direct effects, for a few of the caregivers, their loved ones became easier to care for as a result of their attendance at the day program.

> I had freedom for the day he was there plus the next day because I knew he was still on a high and he wouldn't really need me to be there as much . . . the day that he's there and the day after, it's easier on me.
>
> . . . it seemed like she was happier. Not as many complaints those days.

The day program was also viewed as being enormously beneficial to caregivers. Caregivers felt supported and understood by others experiencing similar challenges and by program staff. They also experienced peace of mind and freedom from the demands of caregiving. For some caregivers, the respite provided by the day program was insufficient to meet their needs.

The analysis of data in this research revealed that both clients and caregivers were highly satisfied with the beneficial effects they perceive as a consequence of attending a day program. Clients derived a great deal of enjoyment and benefit through their attendance and participation. The strengths and benefits identified as most important include activities and services, program structure, relationships with others and the effect that clients noted on themselves and their caregivers. Caregivers identified the activities and services provided both to clients and to themselves and the effects that they noticed in their loved ones as important services of day programs. Most of the client's dissatisfaction and suggestions for improvement centered on the issue of accessibility, particularly the cost of the program and the need for a reliable, cheap form of transportation to be provided. A major source of caregiver dissatisfaction was the lack of accessibility especially transportation difficulties, limited hours of operation and limited program space.

Clients perceived that day programs were effective and enormously beneficial in maintaining and/or improving functional abilities, general health and intellectual functioning. The day programs were viewed as providing clients with meaning in their lives, with broadening their world and a sense of belonging to a larger community. The overall result of improvements in these various areas of the person's life is an enhanced quality of life as the individual retains a sense of dignity and independence, an increased freedom from loneliness and the continuation of meaningful relationships. Caregivers felt supported and understood by others experiencing similar challenges and by program staff. They also experienced peace of mind and freedom from the demands of caregiving although for some caregivers, the respite provided was insufficient to meet their needs.

Chapter V:

Discussion

The purpose of the research was to describe the perceptions of clients regarding the day programs they attended and the impact those programs may have had on the process of managing their health. In addition, the perceptions of participant's primary caregivers and the impact day program attendance may have had on the caregiving role was explored. In this chapter, the results of this research will be compared with the findings of past research. Implications for nursing practice, education and future research will also be discussed.

Study Sample

Most of the clients in this study were male, accounting for 55.5% of the sample. This does differ significantly from the original study in which only 38.2% of the sample were men (Ross Kerr, et al., 1995). The majority of the caregivers were female (82%), being either spouses or daughters as has been documented previously in numerous studies (Horowitz, 1985; Johnson & Catalaus, 1983; Stone, Cafferata & Sangl, 1987). The marital status of clients and caregivers as well as their living arrangements were similar in this sample to that of the overall sample in the original study (Ross Kerr, et al., 1995).

Perceived Strengths of Programs

Both clients and caregivers report being highly satisfied with day programs and were overwhelmingly positive in their discussions regarding the benefits of attending. Clients enjoyed the time they spent at the program and identified a number of aspects of the program that they were satisfied with: activities and services, program structure, relationships with others and the effect of the program on clients and caregivers.

The activities and services that participants reported being satisfied with include recreational activities, the provision of information, nursing services, rehabilitation services and socialization opportunities. Participants reported that recreational activities were fun and enjoyable and provided clients with the opportunity to do things that they would not otherwise have the chance to do. In addition to being enjoyable, participants also perceived them as beneficial in impacting the client's functional abilities, intellectual functioning and overall health and well-being. The actual interests varied widely from client to client with each person identifying different activities and services as satisfying and beneficial. This underscores the need for flexibility in programming and highly individualized plans of care. Neustadt (1985) suggests that a structured, organized activities program will assist clients to become involved with purposeful activity, but must allow for changes according to the mood, energy level, needs and interests of the clients each day. Most of the programs in the present study did allow for flexibility in terms of client interests and offered a variety of options for involvement. Neustadt (1985) maintains that recreational activities assist day program clients in developing self-esteem, self-worth, engaging in socialization and establishing support systems, all of which positively impact well-being and quality of life. Participants in the present study did identify that recreational activities were also socialization opportunities and found them to be beneficial to their overall well being.

In the present study, participants discussed the lack of information available to them in general. Lack of information has been found to be an issue for many caregivers, and can lead to inappropriate expectations, inadvertent mistakes and poor decision making (Green, 1991; Nolan & Grant, 1989; Hirst & Metcalf, 1986; Doyle, 1988). One finding of the present study was that information provided through day program staff about various health conditions, life skills, enhancing functional abilities and planning for the future was helpful to participants in coping with their present situation. Clients and caregivers also identified regular health assessments and monitoring of illnesses and medications as beneficial. Rehabilitation services also assisted clients by helping them to learn how to maintain their functional abilities and independence and by providing them with the support and encouragement necessary to persevere. Finally, meeting new people, engaging in conversation and other social interaction opportunities were very satisfying to participants. In an evaluation study of a day care center in British Columbia, Jackson (1983) reports similar positive evaluations of the day program environment and activities. Social activities with their peers was identified as being the most important to program clients while exercise classes were identified as the most useful activity. As noted above, the opportunity for social interaction and recreational activities were two of the aspects of day programs participants in the present study were most satisfied with.

Participants were also satisfied by the structure of the day program. Although most of the day was planned and organized around a variety of activities, free time was also scheduled in to allow for socialization and the pursuit of individual interests. The opportunity to engage in a variety of activities and the freedom to choose not to participate was important to participants.

Participants were very satisfied with the relationships that developed as a result of their involvement in the day program. Clients developed a sense of belonging in the group as well as companionship and friendship with other clients. Human relationships and social contact with others have been described as being crucial in maintaining quality of life (Ross, 1990; Aller & Van Ess Coeling, 1995). In a study examining what aspects contribute to meaning in their own life, older adults identified relationships with others, religion, services and activities as important sources of meaning (Burbank, 1992). Clients also developed friendships with day program staff and derived a sense of satisfaction from these personal relationships. A number of researchers have looked at the relationships that develop between older adults and health care professionals and the effect those relationships have on the person. Forbes (1994) found that caring relationships with health care professionals are associated again with the degree of value and meaning in one's life. In an examination of the relationships that develop between nurses and long term care residents, Kayser-Jones (1990) found that the interaction and subsequent bonds that develop are important in maintaining quality of life. And in a study of caregivers' perceptions of facilitators and barriers to the use of community services, researchers found that from the perspective of the caregiver, an important aspect of satisfaction was having a special relationship with someone within the system (Malone Beach, Zarit & Spore, 1992). From these findings it is clear that a person giving support to clients and caregivers at a personal level provides meaningful assistance to them.

Similar to the findings in this study, elderly people and their caregivers have reported being highly satisfied with day programs in a number of studies evaluating them (Ross Kerr, et al., 1995; Shantz, 1995). Much of the research provides information about overall satisfaction only and does not indicate what it is specifically that participants are satisfied with. In a study examining clients (n=28) of the Levindale Adult Treatment Center and their closest family members (n=26), 93% expressed satisfaction with the service (Rathbone-McCuan, 1976). Sixty-nine percent of the families considered the day program to be of equal benefit to the aged person and to the family. Hedrick, Rothman, Chapko, Ehreth, Diehr, Inui, Counis, Grover & Kelly (1993) compared the outcomes of a number of adult day program clients (n=668) with those receiving conventional care. Although no significant client or caregiver outcomes were identified, day care clients and caregivers were more highly satisfied with their care.

A number of evaluation studies have examined the effects of day programs on clients alone or on caregivers alone. Theis, Moss & Pearson (1994) evaluated the effect of respite services on caregivers' quality of life, mood and response to caregiving. Caregivers (n=130) expressed satisfaction with the respite that they received although the nature of that satisfaction is not known. Gilleard, Gilleard & Whittick (1984) found that caregivers' satisfaction increases with the length of their care recipient's attendance. They conclude that the association between satisfaction and length of attendance suggests a beneficial effect of day hospital care although the direction of cause and effect is difficult to determine. The length of day program attendance for participants in the present study is not known. Lawton, et al. (1989) also found that caregivers' satisfaction with respite and their perception of an improved quality of life were high. In their study no significant effects were found for caregiver burden or mental health despite their satisfaction.

Weissert, et al. (1989) examined a nationally representative sample of 60 adult day care centers, 529 clients and 168 caregivers to describe the programs and their clientele. Both clients and caregivers expressed high levels of satisfaction with 82% of clients and 92% of caregivers reporting the highest level of satisfaction. Similar to the present study, participants particularly enjoyed the amount of attention they received from the staff. They also identified being satisfied with transportation to and from the center and program hours, findings which were not noted in the present study.

Perceived Weaknesses of Programs

Although participants were highly satisfied and overwhelmingly positive about the programs they were involved with, several weaknesses and suggestions for improvement were identified. Clients and caregivers were occasionally dissatisfied with characteristics of the program, program resources, accessibility, degree of control, treatment, program structure and specific activities within the program. A couple of participants suggested that the focus of the program be broadened to encompass the needs of younger people as well as elderly clients. This finding reinforces the need for program staff to be flexible to provide for individual needs. A couple of participants also noted that program resources were somewhat limited and suggested that more staff, volunteers and materials be provided.

The most significant barrier and source of dissatisfaction for clients and caregivers was accessibility in terms of program costs, transportation, distance, hours of operation and program space. Although other program costs were fairly minimal, the daily fee was a hardship for some people. Many of the programs provided transportation, but it was not always reliable or available when needed. Although all participants were appreciative of the services provided by day programs, hours of operation were identified as unrealistic or incompatible with caregiver needs. Many of these difficulties have also been reported by other researchers (Osterman, 1986; Panella, Lilliston, Brush & McDowell, 1984). Graham (1989) found that adult day care was not available for several caregivers in her study on the days and times when it was most needed. The findings of the present study were similar. Given that care needs and caregiving are continuous, access to services in the evenings and on weekends was suggested. Clients and caregivers also wanted the opportunity to attend more frequently, but were not able to because of lack of program space. Graham (1989) also found that a few caregivers were unable to use adult day care as frequently as they wished to because of financial constraints and that some families had difficulty coordinating transportation to and from the center. Transportation was particularly problematic in the present study for caregivers who were employed and were not available to ensure their care recipient got to and from the program safely. For some clients, particularly those living in rural areas, the distance from the program and the time required to travel to and from it posed difficulties. Almost all caregivers in this study would also have utilized the service more frequently if that option had been available to them. In an assessment of the perceived need for adult day care and actual utilization, Barber, et al. (1993) found that a majority of clients using adult day care rely on friends, relatives or volunteers for transportation to and from the program. They conclude that there are many more people who could use the centers if transportation were made available. In a large study of 642 caregivers of aged Alzheimer's disease sufferers, all participants wished more for additional respite services than for any other type of service (Lawton, et al., 1989). It is clear that barriers such as cost, transportation, hours of operation and program space are factors influencing the degree to which adult day programs are utilized and the benefits derived from them.

Another source of dissatisfaction to some participants was a lack of involvement either in the initial decision to attend the day program or in subsequent decisions affecting them. A few clients felt that they were not treated with respect. Treating others with respect is a value inherent in the health professions and is essential in affirming the person's worth. Enhancing self worth not only assists others to maintain their dignity but also encourages confidence in their own abilities and strengths and positively impacts self esteem (Forbes, 1994). It is clear that clients and caregivers need to feel respected and that they have some degree of input or control over the system. In some cases participants felt that the programs were either too structured or too flexible. Although developing a program which truly meets the needs of the clientele can be a challenge, the objective is to provide opportunities for truly meaningful activity. Neustadt (1985) cautions that "meaningful" activity must be defined by the clients themselves and that there is a fine line between encouraging clients to attend group activities to increase socialization and diminish isolation and allowing them the freedom to be and do what they want. It is evident that an individualized approach is necessary as what is enjoyable and beneficial to one person may not be for others. In a study of caregivers' (n=46) perceptions of facilitators and barriers to the utilization of community services, caregivers raised a number of concerns. Problems such as the quality of care provided and lack of control over some aspects of the program such as scheduling and inflexibility of the system were noted (Malone Beach, Zarit & Spore, 1992). Many caregivers became frustrated as a result of these problems leading some to withdraw from the community services system altogether.

The final source of dissatisfaction was specific activities that clients either disliked or wanted to be engaged in more frequently. Individualized recreational activities such as music and reading and group activities such as exercise and outings have been identified as factors influencing quality of life (Clark & Bowling, 1990). However, Ross (1990) again emphasizes the need to individualize recreation for the elderly as the frequency, duration, location and social context of activities are important determinants of perceived satisfaction. In an evaluation study of a small day program in Alberta, researchers report that the lack of individualization in exercise and recreational programming was an area of concern for clients and caregivers (Neufeld & Strang, 1992). They felt that the recreational activities did not always mesh with the client's needs or interests, resulting in a few clients who left the program. In the present study, one client reported feeling very frustrated over the absence of an activity that was the impetus for him to attend in the first place. As a result, he was seriously contemplating withdrawing even though he felt the program was of some benefit to him.

Perceived Effects on Clients

Day programs were perceived by clients and caregivers as effective in enhancing the client's quality of life. This was accomplished by maintaining or improving functional abilities and health, delaying institutionalization and maintaining or improving intellectual and psychological functioning. Although most clients reported no change in functional abilities, two described an improvement in function leading to greater mobility and independence. This finding of maintenance of physical health and functional ability is consistent with previous research findings (Ross Kerr, et al., 1995; Eagle, et al., 1991; Cummings, et al., 1985). In a randomized, controlled trial, Tucker, Davison and Ogle (1984) examined the effectiveness and cost of day hospital care. One hundred and twenty elderly clients were assessed in activities of daily living (ADL) skills and mood at the time of referral, six weeks later and five months later. Although the day hospital clients demonstrated a significant improvement in the performance of ADL's at six weeks, they were not able to sustain this level of improvement at the five month interval. The researchers conclude that in this age group the improvement in function achieved by intensive rehabilitation is short-lived. As such, maintenance of function may be a more appropriate goal.

A number of other studies have demonstrated that adult day program clients have maintained their pre-program levels of functioning. A study of 1,153 clients using adult day care and homemaker services has shown that the use of these services can help the disabled elderly to sustain, if not improve, their functioning (Wan, Weissert & Livieratos, 1980). And Strang and Neufeld (1990) found that clients of an Alberta day program were able to maintain their level of functioning, thereby delaying the process of deterioration and achieving a degree of health promotion.

Clients also reported a direct health benefit such as feeling more energetic or a controlled blood pressure as a result of attending the day program and engaging in some of the activities and exercises. In a study to determine the extent to which day treatment would improve the health of the community living elderly, Woodford-Williams, et al. (1962) also found that there was an improvement in self-perceived health. A recent study measured outcomes of a program of regular exercise, health teaching and group participation on physical and mental well-being in a convenience sample (n=59) of frail older adults living independently. Researchers assessed hand strength, range of motion, flexibility and blood pressure as indicators of physical well-being using a pre-test/post-test design. After a six month program of participation, statistical improvement was demonstrated in systolic blood pressure and range of motion in the right ankle. All measurements showed a trend in the right direction, even though they did not all reach statistical significance (Dungan, Brown & Ramsey, 1996).

A few clients and caregivers discussed the importance of home and of their independence and attributed their ability to remain at home in part because of the day program. It is generally accepted that no one's first choice is a nursing home and that people are attached to their homes and familiar communities. As Rutman and Freedman (1988) state "the meaning of home for older people is associated with independence in that home is the place in which independence can be maximized and assured. Home has meaning because it provides validation for important dimensions of the individual's identity and positive self-image" (p. 19). Caregivers indicated that they wanted to be able to care for their loved one at home for as long as they were able to manage. This desire to care for a family member for as long as possible is identified in the literature (Smallegan, 1985; Brody, 1985; Strang & Neufeld, 1990).

Although the events leading up to institutionalization are complex and varied, many people are forced to leave their homes because they can no longer live independently. The role of adult day care in supporting elderly people and their caregivers has received a great deal of attention. A number of researchers have concluded that the lack of short term relief from the 24 hour caregiving responsibilities is the primary reason caregivers seek placement (Berman, Delaney, Gallagher, Atkins & Graeber, 1987). Three caregivers in the present study noted that access to the day program assisted them in keeping their loved one at home with them longer than would have been possible without that support. Several researchers have noted that caregivers generally have little contact with formal service providers until a crisis point is reached (Montgomery & Borgatta, 1989; Neary, 1993; Smallegan, 1985). Choices made and decisions reached in a crisis situation may not be optimal, and seeking help at this stage may not allow for the full potential benefit of such services to be experienced. Earlier recognition of approaching need for more care may possibly extend the time before institutionalization is required by mobilizing available resources.

Researchers utilized a randomized experimental-control group study designed to evaluate the impact of respite services to 642 caregivers of Alzheimer's patients. They found that families with respite care maintained their impaired relative significantly longer in the community - 22 days (Lawton, et al., 1989). Collins, King and Kokinakis (1994) studied the family caregivers (n=38) of persons with dementia who had placed their relative in a nursing home. Caregivers were asked about their experiences with community services such as adult day care, in-home services and physician home visits. Forty percent of participants reported that the availability of at least one additional service would have delayed the nursing home placement of their relative. One-third stated that service factors such as the inability to find services and affordability had a strong influence on the placement decision. Although this finding is significant, the majority of the sample did not perceive that additional services would have delayed placement. The researchers speculated that nursing home placement may be inevitable when the demands of the client exceed the family's capacity to meet those demands. If this is the case, it may be that the goal of adult day programs to prevent or delay institutionalization may be unrealistic as well. Perhaps a more realistic goal may be to provide the necessary supports to maintain the elderly person in community living arrangements for as long as possible.

Jones and Salvage (1992) questioned 256 caregivers of elderly people regarding their attitudes towards the caring role. Although most caregivers were highly committed to their role, those who felt that their caring role caused them high levels of stress were more likely to say that they would accept institutionalization for their care recipient and more likely to be able to think of circumstances which might force them to discontinue caring. This finding underscores the importance of providing appropriate support to sustain caregivers in their role.

Strang and Neufeld (1990) employed a descriptive design to evaluate the achievement of the objectives of a day program in Alberta. Information was collected from program stakeholders as well as from clients (n=11) and caregivers (n=14). Similar to the findings of this study, the researchers found some evidence to support the notion that the adult day program delayed institutionalization. They also note that some families did not anticipate the day program influencing institutionalization if the client's condition deteriorated. This finding provides support for the idea that nursing home placement may be inevitable in certain circumstances. And in an evaluation study measuring the effect of respite, 130 caregivers of frail elderly people were interviewed. Forty percent of these caregivers stated that they were less likely to institutionalize the care recipient because of the respite they received (Theis, Moss & Pearson, 1994).

One researcher found that day programs do not delay or prevent institutionalization at all. In an evaluation of four psychogeriatric day hospitals in Scotland, Gilleard (1985) found that the more community health and social services were utilized, the more likely the person was to be institutionalized. This negative finding may be due to changed expectations in caregivers. Seeing so many individuals and agencies looking after their relative may lead them to "disengage" or provide less care than they would have. They may also come to believe that they should not be expected to look after such a disabled person at home and their willingness to accept eventual institutionalization may be raised.

In an examination of research evaluating adult day care programs as an alternative to institutionalization, Harder, Gornick and Burt (1986) reviewed all available evaluation studies. They found evidence of lower utilization of hospitals and nursing homes in five of the six studies that looked at that question. However, they also conclude that because adult day programs serve a group of adults different from those who enter nursing homes, they should be considered supplemental services rather than a substitute to institutionalization. Perhaps a shift in focus from the prevention of institutionalization as an outcome of adult day care services to the provision of community based care that affirms the right of the elderly to quality of life is needed.

A number of participants in this study noted an improved intellectual functioning which they attributed to the stimulation of conversation and games. Clients were more alert, responsive and conversant and one client performed better on mental function tests than he had previously. Turner (1993) reports similar findings in her research examining the effects of an activity program on the quality of life of nursing home residents. Goals of the individualized activity program were stimulation, reinforcement of functional abilities and enjoyment. Mental function, changes in conversation, communication, awareness and knowledge were measured in 52 residents before and after the four week activity program. Significant improvements were observed in cognitive functioning especially in alertness, responsiveness and conversation in the majority of residents. Their quality of life was also significantly improved. Although the client sample may be significantly different from the clientele who utilize day programs, the activities that both groups engage in are similar.

The most significant effect which clients and caregivers perceived was an improvement in psychological functioning. Improvements in mood, responsiveness and in social relationships were noted. In addition to these general effects, participants also noticed a sense of purpose in their lives, an expanded world, a sense of belonging and gratitude for what they have in their lives. A study to determine the extent to which day treatment would improve the health of elderly living alone revealed that those who attended the day program had reduced rates of psychological depression and improved morale as compared to a control group (Woodford-Williams, et al., 1962). A recent study evaluating outcomes of a program of regular exercise, health teaching and group participation found that in addition to improvements in physical well-being, participants reported higher self-esteem and satisfaction with life (Dungan, Brown & Ramsey, 1996). The researchers conclude that the impact of the group was a significant factor in the overall outcome of the program. "Groups fostered a sense of belonging, if not more intimate relationships, that supported improved self-esteem and life satisfaction" (Dungan, Brown & Ramsey, 1996, p. 1192). In the present study, the sense of belonging and relationships with others were identified as two of the most important benefits of attending the day program.

In a U.S. study, Cummings, et al. (1985) randomly assigned patients either to a five day per week day hospital or to an in-patient hospital treatment and rehabilitation unit. They found no differences in health, functional, social or psychological outcomes between the two groups. In the study, the underlying philosophy of the day hospital appeared to be concentrated on medical care and on the physical health of patients rather than on social support or activity programs that are designed to impact quality of life. Thus, the lack of favorable outcomes may be as a result of this particular program's philosophy. Participants in the present study were drawn from a variety of programs including those based on a day hospital and day support model. Although the findings of Cummings, et al. (1985) are significant to those participants involved in day hospital care, their results may have little significance when compared to programs based on a philosophy of social support and activity.

In an evaluation of a day program in British Columbia in which health support was integrated with a strong activities and social support component, the researcher reports favorable outcomes (Jackson, 1983). The view of clients and their families was that their health, functional status and social well-being had improved during day program attendance. Clients were unable to maintain these improvements following the program's closure. A major limitation to the study was the small numbers of clients included in the evaluation.

In a description of an adult day program in Madison, Wisconsin, Neustadt (1985) describes how the group becomes a "community" for its members. Through spending time together and getting to know one another, clients develop a sense of caring and interdependence. "The continual interaction throughout the day among clients and staff adds considerable depth and vitality to the sense of internal community" (Neustadt, 1985, p. 63).

In the present study, clients and their caregivers perceived that the client's quality of life had been enhanced through day program attendance primarily due to effects noted on functional abilities, health, intellectual and psychological functioning and the delay of institutionalization. Other studies utilizing objective measures of quality of life have failed to demonstrate similar improvement as a result of day programs (Eagle, et al., 1991). However, other researchers who have assessed the perceptions of clients, caregivers and program personnel about the impact of day programs have found that they are believed to enhance the quality of life of participants (Burris, 1981; Hunter, 1992). A number of components such as friendship, dignity as an individual, meaningful roles in society, participation as a member of a group, maximum independence and freedom of choice have been shown to positively impact quality of life (Gallagher, 1986; Foreman & Kleinpell, 1990; Burckhardt, Woods, Schultz & Ziebarth, 1989; Dale, 1995). And in

Aller and Van Ess Coeling's (1995) study of what "quality of life" means to long-term care residents, the strongest theme identified was the resident's ability to care for or help others who were more in need than themselves. All of these factors were identified as impacting their quality of life by participants in the present study.

Caregiving Situation

Caregivers described the process of assuming the caring role as a "learning process" and were not in all cases prepared for it. In a study examining the well-being of caregivers, Gilhooly (1984) found that although giving care to a dependent relative rarely had a sudden onset, the majority of caregivers did not expect or prepare for it. Caregivers described three main types of care that they provided: the anticipation of needs in order to prevent illness or injury, hands-on care and protection of the self-image of the person being cared for. Descriptions in the literature of the types of care provided by caregivers varies form minimal assistance with tasks such as shopping to total care with regards to activities of daily living (Hogan, 1990). It has been described as a complex collection of tasks and activities that changes as the frailty and dependency of the care recipient shifts. The work does not necessarily fall into predictable hours or days of the week and may cease only upon institutionalization or death. Bowers (1987) reconceptualized caregiving activities to look at the purpose of the care as opposed to the task as the purpose more accurately represents the experiences, work and stress of the caregiver. In her grounded theory research examining the intergenerational caregiving experiences of middle-aged daughters, five categories of caregiving emerged. Two of the categories - instrumental (hands-on) and protective care - are similar to the ones identified in the present study. An interesting finding of her research is that instrumental or hands-on caregiving is the least important type from the perspective of caregivers but is the most studied. Caregivers consider the emotional well-being and protection of parents much more important than the physical tasks (Bowers, 1987).

Demands of Caring

Caregivers identified that their role was difficult for them at times because of the demands on their time and the effects on them physically and emotionally. It is well documented that the responsibilities of providing care for an older adult can place the caregiver at risk for negative physical, emotional and social outcomes and may compromise the ability of the informal helping network to cope with frail elders on a long-term continuing basis (Zarit, et al., 1986; Green, 1991).

In a comparative study, George and Gwyther (1986) examined the well-being of family caregivers of cognitively impaired older persons in comparison with the well-being of a community sample. Five hundred and ten caregivers were administered several tools assessing physical health, mental health, financial resources and social participation. The results indicate that caregiver burden is experienced primarily in areas of mental health and social participation. This is similar to the experience described by caregivers in the present study. In comparison with the community sample, caregivers averaged three times as many symptoms of stress.

In an examination of working mid-life daughters, researchers found that the time and energy demands of parent care can be overwhelming and can often collide dramatically with being a mother, partner, employee, friend and homemaker (Brody, Kleban, Johnsen, Hoffman & Shoonover, 1987). Overwhelming time and energy demands were not restricted to daughters in the present study - spouses and other caregivers were also concerned about this issue. Another finding of the above research is that the threat of burnout from role overload is very real, especially when the demands of the situation exceed personal resources. The stress can be particularly high when women try to cope by compressing more and more activities into smaller amounts of time. The situation is further compounded as the caregiver eliminates self-nurturing, recreation and relaxation activities as was described by a couple of caregivers in the present study. Nolan and Grant (1989) contend that addressing the needs of informal caregivers has been a neglected area of nursing practice. They conducted a national survey of caregivers in the United Kingdom (n=522) to assess caregiver stress, satisfaction and perceived problems. They found that many caregivers subordinated their own needs almost entirely to those of their dependent.

Jones and Vetter (1984) interviewed a large sample (n=1,066) of elderly people and a smaller sample of their caregivers (n=256) in an effort to determine morbidity of informal caregivers supporting community living elderly. They found that in many cases the role of caring had affected the quality of life and mental well-being of the caregivers. Some reported a curtailed social life which distressed them more than the actual tasks they had to perform, and many caregivers considered that they were under a considerable or an unbearable amount of stress. As was identified in this study, other researchers have demonstrated that a major contributor to caregiver stress is not being able to leave the home without someone to take over caregiving responsibilities (Zarit, Reever & Bach-Peterson, 1980; Marcus & Jaeger, 1984).

Impact of the Day Program on Caregivers

In describing the impact that the day program had on them, caregivers identified support, peace of mind and respite as significant effects of the program. They felt supported by staff and by other caregivers and described that support as important in helping them to cope with their situation. The effect of support groups in assisting caregivers to cope has been evaluated in a number of studies. Greene and Monahan (1989) found that family caregivers to frail elderly persons had significant reductions in anxiety, depression and burden as a result of their participation in a caregiver support group. In another study, researchers examined the psychosocial effects of caregiving for persons with dementia (Brodaty & Hadzi-Pavlovic, 1990). One interesting finding was that while caregivers did have high levels of psychological distress, they were not nearly as distressed as had been reported in previous studies. Because the researchers surveyed caregivers about two years after they joined a support group for dementia suffers and their families, they offer the benefit of the group as a potential explanation for this finding.

Caregivers also identified peace of mind as a significant effect of the day program. This peace of mind resulted because of the effects they detected in their loved one, because they felt that the quality of the program was high and because their care recipient was safe and well cared for and they were relieved of the responsibilities of caregiving temporarily. Strang and Neufeld (1990) report similar findings in their evaluation of the achievement of the objectives of a day program. Working caregivers of frail elderly in their study also described deriving peace of mind on the days their care recipients attended the day program. They worried less because they knew that their care recipient was enjoying their time at the program, safe, well cared for and someone else's responsibility.

Respite or freedom from the demands of caregiving was perceived by caregivers as affecting them significantly. Caregivers were released from the demands of caregiving and were able to use the time to complete tasks or to fully relax. The freedom to do what they wished in that period of time was important to them. Caregivers also identified that their job of caregiving was easier because of the effects the day program had on their care recipient. In some cases, the respite provided by the day program was insufficient to meet the needs of caregivers.

One of the major objectives of day programs is to address caregiver needs by providing respite services which serve to sustain informal caregivers in their caring roles. A number of studies have evaluated the effectiveness of day programs in meeting this objective, with mixed results. In an evaluation of the impact of a day program upon caregivers, Strang and Neufeld (1990) found that "the relief provided to caregivers supported them in remaining in the caregiving role" (p. 18). They caution that although caregivers were able to obtain temporary relief from the stress of caregiving, these stresses were not resolved by having their care recipient attend the program.

In an evaluation study of a day program in British Columbia, Jackson (1983) found that families of clients who attended reported improvements in family relationships and in the health status of the client's elderly spouses. Following closure of the program, families reported increased fatigue, increased financial strain and decreased social activity because of being unable to leave the care recipient alone. In another evaluation study measuring the effect of respite on family caregivers of the elderly, researchers report that respite is an effective intervention (Theis, et al., 1994). Caregivers believed they benefited and reported improvements in physical health (64%) and in emotional health (78%).

A number of other studies employing objective measures of burden have failed to confirm the decrease in caregiver strain through respite services

(Graham, 1989; Lawton, et al., 1989; Gilhooly, 1984). Several explanations may be offered for the failure to benefit significantly. Adult day care alone as a support may not be sufficient to impact the stressors affecting the caregiver. If a crisis situation precipitates the use of respite care, the situation may have already exceeded the caregiving capacity of the informal network. And if respite was not available on the days and times a caregiver needed, access to the services may play a role. Despite the failure of objective measures to confirm a decrease in caregiver strain, anecdotal evidence and qualitative reports which focus on the perceptions of caregivers reinforce its positive impact.

Implications for Nursing

There is a growing number of elderly people in our society who are living longer with chronic disease or with the debilities of old age. The frail elderly live in the community as well as in long-term care institutions. In almost every field of nursing, nurses will be involved in caring for elderly people. Nursing education then must include information on human development in later life and on the continuum of health services that can be provided to promote overall well-being and independence in elderly people. Nursing student educational experiences could include placements in a variety of health services that frail elderly people utilize including adult day programs. This will assist future nurses in recognizing and appreciating the role these services play in supporting the frail elderly and will enable those nurses to be knowledgeable in educating the public about them.

This study suggests that day programs enable clients to maintain their independence and enhances their quality of life. Day programs also provide caregivers with opportunities for socialization and support and provide freedom from the demands of caregiving. Both clients and caregivers are highly satisfied with the beneficial effects they perceive as a consequence of attending the program. Further research is needed to assess the effectiveness of day programs more clearly. The benefits received by older adults need to be explored further and described in more detail. Given that access to day program services is limited, it is necessary to investigate the impact that limited access has. There is a need to continue to focus on the experiences and perceptions of program participants to provide that information. The specific effectiveness of respite services provided to caregivers also needs to be more clearly identified.

Although clients and caregivers were highly positive and very satisfied with the day programs, they were not all satisfied with the same aspects. This underscores the need for flexibility in programming and highly individualized plans of care. Day program staff must allow for individual needs, wants and desires and remain flexible enough to allow for changes in the scheduled activities according to the client's mood and energy level. Those who are planning day care programs must continue to offer opportunities for people to engage in a variety of meaningful activities by ensuring a flexibly structured program and appropriate staffing and resources.

Caregivers do not automatically "know" how to care and feel they are lacking information that would assist them in this role. Nurses can assist caregivers by providing information and also by helping them to identify all of the resources that are available to them. Examples of the information that caregivers require includes knowledge about various health conditions, managing the caregiving role, long term planning, sources of available support, how to apply for appropriate funding, etc. In planning day programs and hiring appropriate personnel, health care professionals such as nurses who are equipped to provide clients and caregivers with information to help them to cope with their situations should be considered.

The relationships that develop among clients and between clients and day program staff is an important source of quality of life for participants. Day program nurses must recognize the importance of these relationships and foster their development by being available to people. They can also encourage relationships to develop among the program clientele by providing unstructured time for conversation and socialization and group activities to promote togetherness and cohesiveness. Nurses also need to recognize the importance of self-determination to individuals. Clients and caregivers need to feel respected and that they have some degree of input or control over the system. Involving participants in decisions that impact them is essential in retaining their trust and enhancing self worth. Perhaps an advisory council composed of adult day program participants and caregivers who play a role in the direction of the program should be considered by day program planners and staff.

There are a number of important implications for public policy highlighted by the findings of this study. As Ross Kerr, et al. (1995) recommended based on their findings in evaluating Alberta adult day programs, the programs should be considered an integral part of the system of long term care. It is clear, however, that barriers to accessibility such as cost, transportation, hours of operation and program space are factors which influence the degree to which adult day programs are utilized and the benefits which are derived from them. Funding to day programs may need to be enhanced to provide for adequate staffing, education for staff and volunteers, and for adequate space and materials to operate. Increased funding to eliminate the need to charge a daily client fee may also be helpful in eliminating the barrier that the cost of the day program imposes on some people. A reliable, appropriate form of transportation must be included as an integral component of the programs. Caregivers who are forced to transport clients in the absence of arranged transportation are deprived of the full intended benefits of respite as they use part of their respite time driving back and forth. Family vehicles are often not appropriately equipped for the travel needs of frail elderly people. The transportation that is arranged must be prompt and reliable as it is very tiring and difficult for frail clients to wait for their ride to arrive. Drivers must be carefully screened to ensure that they are trustworthy and reliable.

The accessibility to day programs can be improved in a number of other ways as well. Day programs could be offered on a regional basis throughout the province to ensure that they are available to those who could benefit. Increased funding could be made available to allow for expansion or greater flexibility in scheduling the hours of operation to include evenings, weekends and holidays. This is especially important to provide respite for caregivers who work outside the home during the usual hours of operation and to allow caregivers to engage in normal, social activities and events that most of us take for granted. Program planners and nurses need to be aware of the barriers preventing access and lobby for system changes that would truly enable day care programs to be available and utilized as an integral part of the long term care system.

Chapter VI:

Conclusion

In this study, the researcher explored and described in detail the perceptions of clients and caregivers about the day programs they were involved with. Study participants included clients and caregivers from around the province in both rural and urban settings, representing both day hospital and day support programs allowing for a broad view. Two major limitations of the study are that data analysis occurred following data collection and that the researcher was not able to confirm her findings with the participants. Despite these limitations, this research makes a unique contribution to understanding the perspectives of both groups that day programs serve - clients and caregivers.

The analysis of data in this research revealed that both clients and caregivers were highly satisfied with the beneficial effects they perceive as a consequence of attending a day program. Clients enjoyed the time that they spent at the program and identified a number of aspects that they and their caregivers were satisfied with: activities and services such as socialization and rehabilitation, the structure of the program, the relationships that developed with staff and other program clients and the beneficial changes they saw in themselves and their caregivers as a result of their attendance.

The activities and services that participants reported being satisfied with include recreational activities, the provision of information, nursing services, rehabilitation services and socialization opportunities. Recreational activities were reported to be fun and enjoyable, providing clients with the opportunity to be involved in activities they would not have the chance to otherwise. Recreational activities were also perceived as positively impacting the client's functional abilities, intellectual functioning and overall health and well-being.

The actual interests varied widely from client to client with each person identifying different activities as satisfying and beneficial, underscoring the need for flexibility in programming and highly individualized plans of care.

Regular health assessments, monitoring of illnesses and medication, and the provision of information, was helpful to participants in coping with their present situation. Rehabilitation services also assisted clients by helping them to learn how to maintain their functional abilities and independence and by providing them with the support and encouragement necessary to persevere. The flexible structure of the day program was important to participants as it allowed for freedom of choice and the opportunity to socialize and pursue individual interests. Perhaps most importantly, participants were very satisfied with the relationships that developed as a result of their involvement in the day program. Clients developed a sense of belonging in the group as well as companionship and friendship with others - clients and staff.

Although participants were highly satisfied and overwhelmingly positive about the programs they were involved with, several weaknesses and suggestions for improvement were identified. Clients and caregivers were occasionally dissatisfied with characteristics of the program, such as age and gender of clients, the degree of involvement in decisions, treatment, program structure and specific activities within the program.

The most significant barrier and source of dissatisfaction for clients and caregivers was accessibility in terms of program costs, transportation, distance, hours of operation and program space. Although program costs were minimal, the daily fee was a hardship for some people. Many of the programs provided transportation, but it was not always reliable or available when needed. Hours of operation were identified as unrealistic or incompatible with caregiver needs and almost all caregivers in the study would have utilized the day program more frequently if that option had been available to them. It is clear from the data that barriers to accessibility influence the degree to which adult day programs are utilized and the benefits that are derived from them.

Day programs were perceived by clients and caregivers as effective in enhancing the client's quality of life by maintaining or improving functional abilities and health, delaying institutionalization and maintaining or improving intellectual and psychological functioning. Although most clients did not experience an improvement or a deterioration in functional abilities, in many cases, they reported a direct health benefit such as feeling more energetic or a controlled blood pressure. Participants also attributed their ability to remain in their own homes and to maintain their independence in part because of the day program. They also noted an improved intellectual and psychological functioning. Clients were reported to be more alert, responsive, and conversant and demonstrated improvements in mood and in social relationships. They also noticed a sense of purpose in their lives, an expanded world, a sense of belonging and gratitude for what they have in their lives.

Caregivers identified support, peace of mind and respite as significant effects of the program. They felt supported by staff and by other caregivers and described that support as important in helping them cope with their situation. Peace of mind resulted because of the effects that they detected in their loved one, because they felt that the quality of the program was high and because their care recipient was safe and well cared for and they were relieved of the responsibilities of caregiving temporarily. Finally, caregivers were provided with respite or freedom from the demands of caregiving. This freedom to do what they wished in the period of time the client was at the day program was important in supporting the caregiver in their role and made the task of caregiving easier in some cases. The respite provided by the day program was not sufficient to meet the needs of all caregivers.

Care of the elderly has become a major concern of Canadian society as the growing elderly population and the demand for services challenges existing resources. Alternatives to institutional services that promote overall well-being, independence and quality of life are desired by elderly people and those who care for them. As one such alternative, day programs have emerged as a viable option in supporting the community living arrangements of frail elderly people. The analysis of data in this research revealed that day programs enable clients to maintain independence and enhance quality of life and provide caregivers with opportunities for support and freedom from the demands of caregiving.

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APPENDIX A: INSTRUMENTS

LIST OF INSTRUMENTS

1. PROGRAM DATA FORM - instrument designed for study purposes, administered to managers of day programs; resultant data describes day programs.

2. REFERRAL AGENCY DATA FORM - instrument designed for study purposes, administered to referral agency managers; resultant data describes day programs.

3. CLIENT INFORMATION FORM - instrument designed for study purposes, information derived from client records; resulting in data describing program participants.

4. SATISFACTION WITH DAY PROGRAM SCALE - instrument designed for study purposes, administered to clients and caregivers; measuring satisfaction.

5. SELF-ANCHORING STRIVING SCALE - a measure of satisfaction with life; administered to clients and caregivers.

6. INDEX OF WELL-BEING - a measure of satisfaction with life; administered to clients and caregivers.

7. QUALITY OF LIFE INDEX - a measure of activity, daily living, health, support, and outlook; administered to clients.

8. PERCEIVED HEALTH STATUS - a subjective measure of past and current health; administered to clients and caregivers.

9. MULTIDIMENSIONAL FUNCTIONAL ASSESSMENT (OARS) - a measure of physical impairment; administered to clients.

10. MINI-MENTAL STATUS QUESTIONNAIRE - a measure of mental status administered to clients.

11. MEMORY AND BEHAVIOR PROBLEMS CHECKLIST - a measure of the frequency of memory and behavior problems often seen in cognitively impaired clients; completed by caregivers of cognitively impaired clients.

12. CAREGIVER BURDEN INVENTORY - a measure of the burden of caregivers; administered to caregivers.

13. FEELINGS ABOUT INSTITUTIONALIZATION - a measure of the drive to institutionalize; administered to clients and caregivers.

14. SOCIAL RELATIONSHIP SCALE - a measure of the quality and quantity of social support; administered to clients and caregivers.

APPENDIX B: INTERVIEW QUESTIONS

GUIDING QUESTIONS FOR TAPED INTERVIEW: CLIENT

Opening Questions:

Tell me what it has been like for you attending the day program.

What effect has the day program had on your life? On the life of your family? Friends?

Supportive Questions:

How did you find out about the program?

What had you heard about the program before attending?

What concerns did you have about attending?

How did you feel the first day you attended? How do you feel now?

How has your life changed since attending?

What do you like best?

What do you like least?

How would you describe the program to others?

Other comments?

APPENDIX B: INTERVIEW QUESTIONS

GUIDING QUESTIONS FOR TAPED INTERVIEW: CAREGIVER

Opening Questions:

Tell me what it was like for you having your _______________ attend the day program.

What effect has the day program had on your life? On the life of your family? Friends?

Supportive Questions:

How did you find out about the program?

What had you heard about the program before your _______________ attended?

What concerns did you have about your _______________ attending?

How did you feel the first day he/she attended? How do you feel now?

How has your life changed?

What do you like best?

What do you like least?

How would you describe the program to others?

Any other comments?

APPENDIX C: CONSENT FORM
(for clients)

Project Title: Evaluation of Adult Day Programs in Alberta

Investigators:

Janet Ross Kerr, RN, PhD
Professor, Faculty of Nursing
University of Alberta
492-6253

Anita E. Molzhan, RN, PhD
Associate Professor, Faculty of Nursing
University of Alberta
492-6279

Sharon Warren, PhD
Associate Professor
Faculty of Rehabilitation Medicine
University of Alberta
492-7856

I understand that the purpose of this project is to evaluate adult day programs in Alberta. I will be asked to complete four brief questionnaires on up to five occasions (if possible on two occasions prior to entering the day program, on admission into a day program, and then two and six months following admission into the program). About 30 minutes of my time will be required on each occasion.

My file/chart will be used to collect information about me and the reasons I am in this program. I will provide the name of a family member or friend who helps me to the researchers so that they can talk to them about the day program.

My name will not be used in any report or talk about the project. Only a code number will appear on any forms or question sheets. All records about this project will be kept in a locked filing cabinet. Only the researchers will be able to see the records.

The study poses no risks to me. If the researchers find out that I or another person has been harmed, it will be necessary to report these findings to appropriate people. If this happens, I will be told who will be notified. The information obtained in the study may benefit others who join day programs in the future.

I can withdraw from the study at any time. I can refuse to answer any questions. Withdrawing from the study will not affect my care in any way. I can withdraw by phoning one of the researchers or by telling them I do not wish to participate.

If the information obtained in the study is used for another purpose, permission will first be obtained from an ethics committee.

Signature of Participant	Date
Signature of Researcher	Date

APPENDIX C: CONSENT FORM
(for informal caregivers)

Project Title: Evaluation of Adult Day Programs in Alberta

Investigators:

Janet Ross Kerr, RN, PhD
Professor, Faculty of Nursing
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492-6253

Anita E. Molzhan, RN, PhD
Associate Professor, Faculty of Nursing
University of Alberta
492-6279

Sharon Warren, PhD
Associate Professor
Faculty of Rehabilitation Medicine
University of Alberta
492-7856

I understand that the purpose of this project is to evaluate adult day programs in Alberta. I will be asked to complete two brief questionnaires on up to five occasions (if possible on two occasions prior to entering the day program, on admission into a day program, and then two and six months following admission into the program). About 15 minutes of my time will be required to do this on each occasion.

My name or the name of the person in the program will not be used in any report or talk about the project. Only a code number will appear on any forms or question sheets. All records about this project will be kept in a locked filing cabinet. Only the researchers will be able to see the records.

There are no risks to my participation in the study. If the researchers find out that I or another person have been harmed, it will be necessary to report these findings to appropriate people. If this happens, I will be told who will be notified. The information obtained may benefit others who join day programs in the future.

I can withdraw from the study at any time. I can refuse to answer any questions. Withdrawing from the study will not affect the care of my friend or family member in any way. I can withdraw by phoning one of the researchers or by telling them that I do not wish to participate.

If the information obtained in the study is used for any other purpose, permission will first be obtained from an ethics committee.

Signature of Participant Date

Signature of Researcher Date